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Shaping the Future for Primary Care Education & Training Project

Integrated Health and Social Care: The Perspectives of People Using Services

A Mixed Methods Analysis

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Executive Summary

Introduction

The aim of this study was to explore service users' perspectives concerning integrated health & social care, and to identify the perceived strengths and weaknesses associated with the current workforce and services provided. The findings will be used to inform the education and training of the health and social care workforce in the North West of England.

The specific objectives were to:

- To explore service users' experiences of integrated health care;
- Identify service users' perceived strengths and weaknesses and future needs associated with integrated health & social care;
- Identify service users' perspectives about the quality of the current health & social care workforce;
- Identify dissonance between workforce and user perspectives on integrated care;
- Explore service users' beliefs about future requirements needed to deliver quality care within a health and social care context;
- Explore service users' experiences and perspectives of health care students within the NHS.

Methodology

A mixed methods approach was adopted for investigation of this topic. Focus groups were used at the exploratory stage, subsequently followed up by questionnaires, and finally by a range of in-depth interviews.

Participants came from across the North West of England and represented three specific Strategic Health Authority areas: Greater Manchester, Cheshire and Merseyside and Cumbria and Lancashire. This report is based on the analysis of 126

completed questionnaires, three focus group discussions, and ten in-depth interviews.

We accessed groups of people whom we judged likely to have had significant experience of health and social care services. In practice, this meant that our samples were drawn from groups of people with fairly complex health and social care needs.

Below is an overview of some of the organisations and client groups who participated in the study:

- Motor Neurone Disease Association;
- Huntington's Disease Association;
- Amputees group;
- Disabled mothers group;
- Multiple Sclerosis support group;
- Substance misuse services;
- Homeless shelters;
- Councils for Voluntary Services (CVS);
- HIV/Aids support group;
- Advocacy group for people with learning disabilities.

Direct users of services and carers of service users took part. Both groups had valuable knowledge to contribute concerning the integration of health and social care and can be categorised as 'service users', albeit that their reasons for using services may differ somewhat.

Findings

There were many accounts of good practice in integrated health and social care, where workers from different professional backgrounds seemed to work together successfully in a coordinated way. A range of different working partnerships were identified by service users. Here are a few examples of the partnerships describe:

- Social Worker, OT and Physiotherapist (described by the participant as being part of the local 'Integrated Care Team');
- Social Worker and Community Psychiatric Nurse;
- Men's Health project partnership between Primary Care Trust and Social Services (Social Care Support Workers and Nurses working in partnership);
- Hospital Nurse, Dietician, Social Services Day Centre staff;
- Age Concern, Crossroads, Health Visitor.

Although there were examples of good working partnerships there were equally many examples of what might be termed 'disintegrated' care, where different services failed to communicate with each other, and passed responsibility for solving service users' problems onto other workers (the 'it's not our problem' narrative).

Empowerment of service users is obviously a key policy goal with regard to health and social care. Accounts were given by people who felt enabled to make major decisions about their own care because of workers advocating on their behalf or, for example, as a result of the Direct Payments scheme. A greater number of participants did not feel empowered regarding organisation of care, though, and described their attempts to secure appropriate services as a constant struggle. A perceived lack of integration in health and social care services apparently made this situation worse. Participants often did not appear to feel listened to, or consulted upon their views regarding health and social care.

The provision of home care services was an issue of much importance to the participants in this study. There

were a few reports of home care agency workers who provided a valued service, and who communicated well with other workers. The majority of reports concerning home care services were negative, however, with consistent concerns expressed about continuity of care, professionalism of workers, and their associated communication skills.

Recommendations

The study has indicated some clear areas which should be addressed with respect to integrated services, and to the training of the health and social care workforce:

- Proactive consultation mechanisms are needed to identify the types of services that users would like to see in place. Current arrangements are too passive – the service user has to take the initiative;
- Include clear models of good practice in integrated care in the training of health and social care workers;
- Find ways of capitalising on obvious service user enthusiasm for training;
- Involve service users in interdisciplinary training sessions to enhance workers' appreciation of user perspectives;
- Place a greater emphasis in training on the use of basic communication skills (especially listening skills) in direct client work;
- More opportunities for health and social care workers to train together to enhance appreciation of different professional perspectives/crossing of professional boundaries;
- Significant increase in investment in training for home care agency workers;
- Establish professional qualification pathways for home care workers;
- Raise both workers' and service users' awareness of the meaning of integrated health and social care: that is, not only integration between work of different health and social care professionals, but also integration between work of statutory and non-statutory organisations, and between the work of home care staff and 'professionals';
- Emphasise that partnership working means partnership between workers and service users – not only between workers;
- Address workload allocation of health and social care workers to allow time for meaningful interaction with clients.

The Project Context

Introduction

Collaboration and partnership working between Higher Education and the NHS is an essential requirement for effective delivery of care (Universities UK 2003). The North West Universities Association (NWUA) and the North West Development Agency (NWDA) are two organisations at the forefront of creating such alliances. The research project, Shaping the Future for Primary Care Education and Training Project is a collaborative partnership between both these organisations and seven North West Higher Education Institutions. In addition, the project brings together for the first time all the key partners in the health, social care and education sectors who are involved in supporting the delivery of integrated health and social care in the North West Region.

These include:

- The North West Development Agency who are funding the project as part of their key target areas, i.e. Health;
- The North West Universities Association;
- Three North West Strategic Health Authorities;
- Primary Care Trusts;
- Social Services;
- Higher Education Institutions and Further Education Colleges.

The project has a project management and development team and a participative Steering Group, which it is anticipated will be the precursor to a close regional partnership intended to create real synergies at a regional level. For ease of implementation the project has been divided into a series of Work Packages, based on the key objectives, each led by one of the

partner Higher Education Institutions.

Aim and objectives

The main aim of the project is to identify the evidence base for delivery of integrated health and social care; the skills and knowledge required to deliver this care, together with the current and future education and training needs of the North West of England Primary Care Workforce.

The key objectives of the project are:

- To provide a comprehensive systematic review of the evidence base for integrated health and social care services within the regional, international and national contexts;
- To develop a Benchmarking Tool for achieving best practice in collaborative working and delivery of integrated health and social care;
- To develop a course finder tool and map the Higher Education/Further Education provision of education and training which can support the delivery of integrated health and social care services;
- To identify visions for the future, for both the health and social care workforce and service users, on education and training requirements needed to deliver integrated services;
- To develop and pilot an Education and Training Needs Analysis Model (ETNA) for identifying the education and training needs of the primary care workforce to meet the NHS and social care agendas.

Conclusion

Ensuring that the health and social care workforce is educated and trained to meet changing community needs is essential for current and future delivery of services. This project is an opportunity for a number of key stakeholders in health, social care and education to collaborate in a new and unique way to address this, both directly through the project outcomes and indirectly through creating communities of learning across the North West Region.

Chapter 1:

Background to Project

1.1 Introduction

This study investigated people's perspectives concerning the notion of integrated health and social care. The key question asked was whether health and social care services seemed to be integrated, from the point of view of those making use of them.

A wide variety of recent policy initiatives indicate the current significance of integrated provision in the delivery of health and social services (Department of Health 1997, 1998, 2000, 2001 & 2002). The same initiatives have pointed to the importance of consultation with service users. Many words have been written on the need for effective partnership between people who provide services and the people who use them, with the proliferation of phrases such as 'empowerment', 'consumer involvement' and 'stakeholders'. The development of consultative mechanisms such as Patient's Forums, Patient Advice and Liaison Services, and the Commission for Patient and Public Involvement in Health have all been part of this agenda.

The principles of integrated care and consultation are well established in policy documentation, but there has as yet been no systematic attempt to examine both of these topics together. That is, to 'consult' directly with the people who use services as to whether they are experiencing integrated services. This study attempts to fill that gap. If the training of health and social care workers is to be directly relevant to the needs of people who use services it is obviously crucial that their perspectives are used to inform that training.

The overall aim of this study was to explore service users' perspectives of integrated health & social care and

identify the perceived strengths and weaknesses associated with the current workforce and services provided.

The specific objectives were to:

- To explore service users' experiences of integrated health care;
- Identify service users' perceived strengths and weaknesses and future needs associated with integrated health and social care;
- Identify service users' perspectives about the quality of the current health & social care workforce;
- Identify dissonance between workforce and user perspectives on integrated care;
- Explore service users' beliefs about future requirements needed to deliver quality care within a health and social care context;
- Explore service users' experiences and perspectives of health care students within the NHS.

1.2 Defining consultation

A basic definition of integrated health and social care was used as a starting point for this project:

"Care that is determined by partnerships between health and social care agencies and users/carers for the health and well being of the (local) community."
(www.pcet.org.uk)

The stated aim of the study was to shed some light on the second aspect of this definition; that is, the extent to which the said partnerships have in fact impacted on the health and well being of users and carers. The above typology, however, envisages a situation where partnerships between agencies, users and carers are already in existence. A key question for our study was to judge, from the perspective of service users and

carers, *whether* such partnerships exist.

In attempting to create a foundation for effective partnerships between service users and agencies consultation has moved to the forefront of developments in health and social care policy. The *National Health Service (NHS) and Community Care Act* in 1990 placed an obligation upon local authorities to consult with users and carers about the implementation of community care plans (Farrell, 2004). Further documents in the 1990's continued this emphasis. The most significant document for the development of the NHS released by the current government was the White Paper, *'The new NHS: Modern, Dependable'* (Department of Health, 1997). Amongst a variety of other promises for the restructuring of the NHS the White Paper aimed to encourage a patient-centred NHS culture, and to make the NHS 'accountable to patients, open to the public and shaped by their views'.

The NHS Plan followed in 2000 with a 10 year programme of modernisation for the NHS (Department of Health, 2000). Chapter 10 outlined key changes that were envisaged for patients including:

- Expansion of the 'Expert Patient Programme';
- Better information on local services to inform patient choice;
- New patient advocacy and liaison services – NHS trusts to get patient views on services;
- The creation of Patient Forums for every NHS trust to allow service user input into how services run;
- And in a move towards enhancing integration of health and social care a new duty for local authorities to evaluate local NHS performance through 'scrutiny

committees'.

Many of these proposed interventions are now in place with, for example, Patients' Forums having been introduced in 2003 as a way of replacing the old Community Health Councils. Patients' Forums have been instituted in all NHS trusts with the aim of actively engaging the community to find out what patients, carers, and families think about health services. They aim to monitor service delivery from the patient's perspective and to work with trusts to bring about improvements and inspect every aspect of care used by NHS patients, including 'NHS care provided by the independent sector' (Chambers et al 2003).

The Expert Patient programme is designed to impact on people with long term health problems and encourage them to take more control over their health by learning about, understanding and managing their condition. Practically, this involves people attending a course led by someone with a long term health condition for six weeks (<http://www.expertpatients.nhs.uk/wh at.shtml>).

The Independent Complaints Advocacy Service (ICAS) is another avenue for patients input into the organisation of health services and was launched in 2002. The aim of this development is to help people to articulate their concerns and navigate the often complex complaints system. The Patient Advice and Liaison Services (PALS) was also launched in 2002 and aims, amongst other things, to provide information to service users about local health services, and put them in contact with voluntary organisations and support groups, and also to put people in touch with independent advocacy if they would like to complain formally about their care.

Much of the impetus to this rapid development in levels of consultation with service users came from the *Health and Social Care Act* of 2001 (Department of Health, 2001). This was a very significant piece of legislation in terms of the overall integration of health and social care services, and Section 11 of the Act was most closely concerned with the needs of the service user. Section 11 imposed a duty on NHS institutions to arrange to involve and consult patients and the public in planning services, with respect to proposals concerning changes in the ways that services are provided, and concerning any decisions that affect how the health and social care services they receive operate.

The Health and Social Care Act, as its name implies, was also a key factor in the enhancement of Social Services' role in the provision and development of health care services. One important result of the Act was the formation of Local Authority Overview and Scrutiny Committees which were given powers to examine local NHS provision as part of their wider remit in health improvement and reducing health inequalities in their locality. These committees are obliged to gather evidence, including the views of service users, and make regular reports and recommendations to their NHS counterparts; as well as submitting regular reports to the national Commission for Patient and Public Involvement in Health. The Commission is responsible for overseeing Patients' Forums in all English Primary Care Trust's (PCTs) and for evaluating the national system of patient and public involvement.

As the above review suggests there have been many pronouncements and initiatives concerning the representation of service user

perspectives with respect to health and social care services in recent years. As with the general restructuring of the NHS, though, the amount of policy development concerning consultation seems hard to keep up to date with – both for those involved professionally and those whose views are sought in the form of consultation. A key part of the rationale for abolishing Community Health Councils was the apparently small number of individuals who took part in comparison to the large communities whose views they purported to represent. The development of Patients Forums, Patient Advice and Liaison Services and so on are meant to offer a much more thorough and comprehensive means of consultation with a wider cross section of people. The basic premise is that the variety of measures described above will allow for a more authentic representation of user perspectives. It is too early to say whether such a goal will be realised, but the complex range of initiatives available presents a fairly difficult scenario for the public to negotiate.

1.3 Defining user involvement

User involvement itself is a very broad term and one which can carry many meanings – ranging from answering simple questions for 'patient satisfaction surveys' to significant involvement in decisions about service development, resource allocation and planning. Some attempts at user involvement have been criticised for their ambiguity concerning what exactly is meant by phrases like user involvement or consultation. Barnes and Walker (1998) make the following point with reference to the consultation procedures proposed under the *NHS & Community Care Act*:

"If people are canvassed for their views about service development priorities during collective consultation exercises, but are then given no say over when the home help will call, nor any opportunity to discuss and agree priorities for the tasks she should undertake, the outcome will be frustration and cynicism rather than feelings of empowerment." (Barnes & Walker 1998, p.203)

Empowerment is a term very much in common currency with regard to service provision with the notion that service users should be empowered or enabled to make concrete choices regarding the arrangements of their care. The advent of the Direct Payments scheme, for example, has been very much part of this policy direction. As Barnes and Walker suggest, though, it is important to be circumspect about the use of phrases like empowerment and involvement in these contexts.

Lindow and Morris's (1999) evaluation of the '*national user involvement project*', (focusing on four user involvement initiatives across England) suggested that consultation was only likely to be viewed as meaningful if associated changes in services were demonstrable to service users:

"All the service user groups said that appropriate feedback about any changes that have been made as a result of consultation was essential if they were not to feel exploited." (Lindow & Morris 1999, p.2)

It is useful to conceive of user involvement with respect to the levels at which it can take place. Thus, people can potentially be involved in decisions about their own care, but also with regard to debates about the general range and quality of current services, and ultimately in terms of

priority setting and planning for future service development (Chambers et al, 2003). Much of the consumer involvement within the NHS seems to have centred around patient satisfaction surveys, which have attracted some criticism regarding simplistic assumptions about the meaning of 'satisfaction' in this context (Williams et al 1998). It is also possible to question the representativeness of satisfaction surveys as they seem most likely to represent only the views of those who are particularly motivated and indeed able to fill in questionnaires. Ovretveit (1997) suggests that the NHS may have much to learn from Social Services and related voluntary organisations, as they appear to have a longer history of involving clients than the NHS; especially in involving carers and users in assessment, care planning and reviews.

Inter-professional education is promoted within government documents as a means of encouraging professionals to be more user centred in their work. One Department of Health guidance document suggests that such education could develop a workforce capable of "looking at healthcare mainly from the patients' perspective and in which professional skills are combined to support patient centred care" (Department of Health 2002, p.23). The exact mechanism by which such training is likely to produce more enlightened workers, or the delivery of more patient centred care, is not spelt out within this document.

There are a number of ongoing initiatives, however, which may approximate to the forms of education that are being promoted here. At the Universities of Salford, Coventry, and Warwick service users and carers have been directly involved in the training of health and social

care professionals. In these initiatives service users are directly involved in the delivery of teaching and organisation of courses for both nurses and social workers (Institute of Health at Warwick, 2005 <http://www.chssc.salford.ac.uk/partnerships/cats.php>).

1.4 Defining users

Another important debate of relevance to our study is the terminology used to describe people who use health and social care services. Any attempt to define or label a group of people is never politically neutral, and each label is predicated upon a particular world-view of the relationship between users and providers of services.

The currently popular term of 'service user' has been criticised for potentially negative associations:

"Whilst 'user' may be appropriate in some settings where the aim is to discourage any dependency, it gives the impression of someone exploiting the practitioner and the service and does not advance the idea of a partnership for co-service." (Ovretveit 1997, p.84)

The service user term has tended to be used as a supposedly 'value-free' alternative to words like 'patient' with its associations with notions of passivity and being subject to treatment. As Ovretveit (1997) suggests, however, there are also clear value judgements that people may associate with the 'user' word.

'User groups' are relatively widespread and have been described variously by their members as 'self help' groups, 'pressure' groups, 'advocacy groups' or 'consumer' groups (Barnes 1999). The 'consumer' word became especially popular through the 1990's with regard to the NHS internal market, where the

notion of consumer choice was extended from day-to-day consumption of 'consumer goods' to include choices made with regard to health and social care. Use of the word 'consumer' with reference to people's participation in health and social care, therefore, suggests a market oriented view of relationships. Boote, Telford and Cooper (2002) found a lack of enthusiasm for the word when exploring health professionals' views on terminology. Workers suggested that the phrase consumer made them think of supermarkets and that it carried overtones of sickness and disempowerment (Boote et al, 2002). They also report on another study, where the word 'user' was also apparently rejected as a label because of perceived associations with substance misuse.

Barnes, Carpenter and Bailey (2000) charted the development of terminology to describe user involvement in Department of Health guidance documents. They suggest that Department of Health guidance on user involvement changed from 'consumerist approaches' of the early 1990's, through 'empowerment' approaches in the mid 1990's to the currently favoured use of the word 'stakeholder'. Stakeholder is now used as a term to describe all those people who have a 'stake' in health and social care: such as people using services, as well as carers and professionals. The term is one which appears often in the documentation of the General Social Care Council; the body responsible for setting professional standards for Social Work.

A related point which is of particular significance to our study is the conceptual distinctiveness between the concepts of service users and carers. Both of these groups of people could be described as service users. A person with motor neurone disease, for example, will need to use health and social care services, but so will a relative who may be providing care. The carer is, therefore, a service user in so far as she needs to use services to help her care for her relative. Of course, some would argue that this point underlines the absurdity of the service user epithet, in that we will all be users of health and social care services at times. Since we could all be called 'service users' this argument suggests that the phrase becomes useless as a label to denote a particular group of people.

Barnes and Walker (1998) make a more fundamental point about this discussion in stressing the need to distinguish the 'separate voices' of carers from those they care for. Both groups will have differing but, at other times, similar concerns to address by the health and social care workforce. It is important that neither group's views are taken to be simply representative of the other's perspective; albeit that their concerns may have much in common. It is not clear that this distinction has been acknowledged in existing mechanisms for consultation, such as the Patients' Forums. Much thought needs to be given to ways in which people with limited verbal communication, for example, can be allowed to express their concerns through such avenues. Barnes and Walker (1998) make a related point in discussing issues of representation amongst groups of elderly people:

"Collectivities of older people could develop their own representatives, as have other groups, but our argument.....is that both politicians

and officers in welfare services have responsibilities to seek out the 'quiet voices' which are too often not heard." (Barnes & Walker 1998, p. 204)

User groups and voluntary organisations may be made up of some of the 'louder' voices in a given population and are not necessarily representative of those they claim to represent.

The user movement emerged initially from the efforts of people using social care and welfare services (as opposed to health services), with the main developments dating from the 1980's and being concerned primarily with empowerment of people with disabilities. The user movement in this respect has been instrumental in highlighting the fact that effective service user involvement necessarily involves a challenge to the political status quo:

"Welfare service user movements point to a changed relationship between service users and social policy, based on service users as active participants in policy and analysis rather than passive recipients. They question the traditional social production of both policy and research. They have asserted the moral right of service users to be included in debates and developments which affect them in line with their civil and human rights and highlighted the ethical, philosophical and methodological problems of their continued exclusion" (Beresford and Holden 2000, p.980)

As Beresford and Holden (2000) suggest, service user involvement not only questions the social production of policy, but also the production of research. The implications of service user involvement for the social production of this particular study.

Chapter 2:

Research Methodology

2.1 Introduction

A mixed methods approach was adopted for investigation of this topic. Focus groups were used at the exploratory stage, subsequently followed up by questionnaires, and finally by a range of in-depth interviews.

The mixed methods approach adopted here can be described as a form of 'triangulation'. Triangulation generally refers to the use of a variety of different research methods to investigate a single topic. The word is not used in this report, however, to refer to standard notions of triangulation as an attempt at 'confirmation' of a particular understanding of the research problem. The three research tools chosen here were done so with the aim of 'completeness' in understanding of participants' perspectives (Jick, 1983). The underpinning belief behind this strategy is that it is never possible to confirm that any one interpretation of a social issue is a wholly accurate one. This perspective suggests that it is not possible to get a 'true' or objective representation of other people's perspectives through research. Rather, the goal of triangulation, according to this standpoint, is to use complementary research methods to achieve as 'complete' an understanding as possible.

The focus groups were designed as an exploratory stage of the project: to allow participants the opportunity to discuss their ideas about health and social care in a loosely structured fashion (see Appendix 1 for a copy of focus group discussion guide). The particular value of focus groups is that the interaction amongst participants brings up issues that may not be directly prompted by a researcher question, as focus groups

are run with only minimal intervention on the part of the moderator. Data may be gathered as the result of participants' responses to a specific question, but also through group members elaborating and discussing associated topics amongst themselves. This procedure allows for a relatively detailed exploration of people's thoughts on a topic. The findings from the focus groups in this study provided a valuable form of data in themselves, and were also used to inform the development of the subsequent questionnaire. We decided to carry out one focus group discussion in each of the three Strategic Health Authority (SHA) areas with which the overall Shaping the Future project was concerned. These areas were Greater Manchester, Cumbria and Lancashire and Cheshire and Merseyside.

In order to get an informed understanding of our subject we decided to access groups of people whom we judged likely to have had significant experience of health and social care services. In practice, this meant that our samples were drawn largely (though not exclusively) from groups of people with fairly complex health and social care needs. Below is an overview of some of the organisations and client groups who participated in the study:

- Motor Neurone Disease Association;
- Parkinson's Disease support group;
- Huntington's Disease Association support group;
- Disability Resource Centres;
- Age Concern;
- Amputees group;
- Disabled mothers group;
- Multiple Sclerosis support group;

- Substance misuse services;
- Homeless shelters;
- Councils for Voluntary Service (CVS);
- Day care centres (various);
- HIV/Aids support group;
- Advocacy group for people with learning disabilities.

Participants came from across the North West of England and represented the three Strategic Health Authority areas mentioned above. Direct users of services and carers took part, as we believed that both groups would have valuable, and possibly contrasting knowledge to contribute regarding the integration of health and social care.

We decided to use semi-structured postal questionnaires in order to gain a wide coverage of our target groups, in view of the limited time and resources available to us. Although postal questionnaires are well known for their poor response rate we judged that by sending out a large number of them we would still hopefully be able to get a sufficient return for a comprehensive analysis of our topic. We decided to send out 1500 questionnaires.

The questionnaire was thoroughly piloted amongst the target audience and others (see section 2.2). A local advocacy group for people with learning disabilities assessed the questionnaire for its accessibility and produced a user friendly version that was subsequently used and adapted for the final version. We decided at the outset that assistance in completing questionnaires was an acceptable way of accessing the views of people who may have had difficulty expressing their views in any other way. On a methodological level such an approach raises questions about authenticity of responses. If

questions are asked and recorded by a second person, one has to consider that those responses may not be clearly reflective of the perspectives of the initial participant. We believe, however, that the potential methodological problems are outweighed by the advantages to be gained in getting at least a partial insight into the views of socially excluded people. This is an important issue for research which focuses on marginalised people. Those people whose knowledge is least likely to inform policy are also those who are least likely to have their 'voices' heard through conventional communication channels.

In order to complement the questionnaire data, in-depth (or loosely structured) interviews were also carried out with individuals from the geographical study area. Such interviews offer the opportunity to gain a detailed insight into the way interviewees perceive the topic under investigation. In-depth interviews allow much more time for the individual to reflect on the subject and to present a more complex interpretation of the research question than is possible through the use of a self-administered questionnaire. They also offer participants the chance to check their understanding of questions, and for the interviewer to ask participants to clarify and elaborate upon their thoughts. A key objective was to gain a greater appreciation of the meanings that participants attach to their experiences of health and social care. Questionnaires are not especially useful in addressing 'meaning' because of their structured format and general brevity. Our questionnaires were useful in attaining a broad overview of people's perspectives, but the in-depth interviews allowed us to explore participants' responses in

more detail, and to follow up particular topics that had seemed particularly significant in the questionnaire responses. A target of 15 in-depth interviews was set – five in each of the Strategic Health Authority areas.

The next section of the report is Geraldine Nicholson's account of the fieldwork process. Her account gives an informative description of the process by which contacts were made and data collected. This description is a valuable resource for anybody else attempting to set up a similar study on the perspectives of potentially vulnerable and marginalised people. It has much to say on the challenges of obtaining authentic research data in this context and on associated ethical dilemmas. Geraldine's analysis has much in common with contemporary notions of 'reflexive analyses' (Mauthner & Doucet, 2003), especially in her discussion of the researcher's emotional responses. In keeping with the principals of a reflexive analysis Geraldine's account is written in the first person.

2.2 The Research Experience Acknowledgements

In introducing this research experience I would like to begin by acknowledging the contributions made by all those who became involved in this project. They made the research process, of this particular part of the overall project, an incredibly powerful experience. I felt that many of those accessing services welcomed the opportunity not only to have their views heard, but hopefully to have a direct input into 'Shaping the Future of Integrated Health and Social Care' in the North West.

Throughout the research process I have had the privilege of meeting and communicating with some amazing

individuals. These people have given, and continue to give, a great deal to their communities. These ranged from very dedicated professionals, who were willing to go the extra mile in patient care, to others who gave selflessly for little, or no financial reward. This latter group included members of the voluntary sector who were working tirelessly to offer support to those in need. Through a genuine interest in the project there were others who offered practical help with piloting, distribution and collection of questionnaires.

Most importantly, I need to acknowledge the research participants themselves, that is; those accessing services and their carers and ex-carers. Some of whom allowed me an insight into the intimate details of their daily lives (including their experiences of service provision), conditions they were coping with, and their philosophical thoughts on dealing with death.

Introduction

As a researcher on the team at the University of Central Lancashire (UCLAN) I have had the privilege of gathering the views of 'service users' and/or their carers for the Shaping the Future Project. In order to give an understanding of the research process I intend to give a brief account of the researcher experience. This will include anecdotal accounts of individual interactions and the perceptions and the responses of the researcher within these situations. Although this report includes some methodology its focus is on the researcher's emotional observations and reactions which are often omitted in research papers.

My part in the initial stage of the research began with finalising the questionnaire. This was carried out by a process of piloting, which was

completed in a number of stages. Prior to the first pilot the help of a group of people with a generalised knowledge of research but outside of academia was enlisted. These included, an executive director from Tameside Borough Council, an advisor to the Office of the Deputy Prime Minister, an engineer, a social worker, a police constable, a manager from Bedford Borough Council, a retired health professional, a district nurse and a school teacher. This technique was specifically used to refine the structure of the questionnaire, because it was thought that, if these people found difficulty with the clarity and answerability of the questions, then the more vulnerable groups we needed to reach could not be expected to engage with the project. This diverse range of people drew attention to the deficits in the original questionnaire, highlighting 'issues of accessibility of language' and 'user friendly' format. For example, the overuse of academic language and the ambiguity of the questions themselves. Also comment boxes were changed to lined writing areas which, it was suggested, would encourage people to give their comments more freely.

From the information gathered during this pre-piloting process the questionnaire was refined accordingly. From this stage the questionnaire was now ready to be piloted among people who reflected our target group. For this first pilot I enlisted the help of a group of eleven people, six of whom were service users with a varied range (both chronic and acute) of health and social care needs and five who were carers or ex- carers.

This first pilot highlighted one or two areas for further improvement in usability. It also raised some new issues not previously considered; for example, the impact the

questionnaire might have on people who may already be in crisis, or may, at least be living stressful lives. Considering the ethical principle of 'do no harm' we included a separate sheet with a list of contacts who could offer practical advice and emotional support (see Appendix 7). Prior to my involvement in the project, 'Preston People First' (a disability resource centre) had been enlisted to produce a user friendly version of the questionnaire for people with learning disabilities. So now we had two versions of the questionnaire but because distribution was in part blind to the cognitive abilities of individuals, it was decided to merge the two versions of the questionnaire. A balance was struck and picture cues were included where appropriate.

A second pilot was initiated, this time with the help of people from the previous two groups and also with three new persons who were people with moderate learning disabilities. At this stage it was recognised that there would still be a number of individuals who would not be able to participate without specialised support. In recognising this, volunteers would be vital to enable participation from a wide range of individuals. It was also recognised that even with this support there would still be some persons outside the scope of the project.

One issue that came across quite strongly in all three consultation stages was that the term 'service user' did not seem to sit comfortably with many of the participants.

Please consider the following quotes:

1. 'Service user' as a label is unpleasant sounding and I don't imagine the general public would necessarily be aware of what it means.'

2. 'What does this mean – internal jargon'
3. 'I don't like to be referred to as a 'user'
4. 'I care for my wife and I object to you calling her a 'user' say it again and I'll thump you.' [This was only one of similar comments made during in depth interviews]

So what would people like to be called? I asked people what term they would prefer. With respect to the medical context and use of health care services people actually stated that they preferred the traditional term 'patient'; or more generally 'a person accessing services'.

A person independent of the project proof read what was thought to be the final draft of the questionnaire, and spotted a crucial oversight in the structure of a question. This was that we had asked a question that required both a negative and positive response, e.g. "What did you **like** or **not like** about the health care services you received?" This was set right by asking two separate questions rather than one i.e. "What did you like about the health care services you received?" and "What did you not like about the health care services you received?" with separate spaces for answers to each. These changes not only brought clarity to the questions for the participant but also made it easier for the researcher to record and interpret the data on return of questionnaires. The UCLAN team agreed that the questionnaire was now ready for distribution.

The lessons learned from piloting therefore were: to de-jargonize the questions, add picture cues where appropriate, to include information on help and advice, provide support where necessary and as a final check, independent proof reading is invaluable. The provision of support

was more crucial than we had initially realised, and unfortunately we had not at this stage even considered brail, or language translation, or those individuals who had other types of literacy needs.

Initial contacts

For questionnaire distribution I began by contacting people within the University of Central Lancashire who had links to community groups. My first port of call was the late (and my very dear friend) Dr. Eileen Johnson who was the Comensus Project leader at the University of Central Lancashire. The Comensus Project facilitates the involvement of 'service users' and 'carers' in teaching, research and development activities. It also maps 'service user' involvement in projects across the University. It was through Eileen's leadership on this project and through her previous community work, in which she had made contacts with the gatekeepers in the voluntary sector, that she was able to set me on course with who to contact and where to begin. Her contribution was invaluable to this initial stage of distribution of the questionnaires. So too was her ongoing support throughout the majority of my involvement with this project.

Next I contacted Janet Fakiri, Communications Co-ordinator, from the Centre for Ethnicity and Health in the University of Central Lancashire, as we needed to be sure we were including the views of Black and Ethnic Minority groups across the region. I then began to contact a number of Councils for Voluntary Services (CVS's) who were extremely helpful. Also I made contact with a number of Primary Care Trusts (PCT's) and Social Service Departments throughout the North West region.

A very interesting comment was given by a member of senior management. This person said that they could not see the point in the distribution of the questionnaires on their patch because:

'There are no gaps in training or in service provision in our area.'

This comment proved very useful in motivating some of the more reluctant gatekeepers to play a part in the distribution of the questionnaires. On hearing this professional's comment they seemed to realise that this might be at least one opportunity for their members to voice their opinions of their experiences, either in support or as a form of redress to this comment.

Taking into account the wide geographical area we needed to cover, the poor return rate of postal questionnaires, and thirdly, the poor health participants (who already had great demands on their time), it was decided that our distribution target needed to be substantial in order to facilitate a reasonable sample size.

Therefore, 1500 questionnaires were distributed across the three SHA areas the project covered i.e. Cumbria & Lancashire, Cheshire & Merseyside and Greater Manchester. This was done in a number of ways: some were posted to various CVS's and some to individual societies, yet others were delivered by hand to local organisations within the community. Because many organisations were only offering to take five or ten questionnaires, I began to realise that this was going to be an enormous task and that if we were to meet the deadlines we would need to enlist help.

From early on substantial interest had been shown in the project from a diverse range of individuals some of whom were keen to be involved.

They had offered help in a number of ways; some offered help with piloting the questionnaire as already discussed, and three 'self selected' volunteers offered help with the more time consuming tasks. They helped in the following ways:

- Physically distributing the questionnaires to local community groups;
- Sitting with individuals who needed help completing the questionnaires;
- Telephoning organisations to make initial contacts;
- Help with the mail outs.

Although the volunteers had offered their time unconditionally, on recognising the degree of their input, the team agreed that we should offer something in return for their help. They were given token payment in the form of supermarket gift vouchers. This in no way reflected the amount of work they undertook.

The three volunteers had been given brief details of the project as a whole with a more in-depth explanation of the part of the project assigned to UCLAN. They had all been Criminal Records Bureau checked and were aware of the ethical issues surrounding working with vulnerable people i.e. issues of confidentiality and data protection. The volunteers have given their permission for this brief insight into their backgrounds, although their names have been changed to protect anonymity. They shall be known as Harry, Hermione and Mrs. Weasley.

Harry is a male of mixed race which can (in some circumstances) have its own issues of alienation, but in this case it seemed to give him easier access to some minority ethnic community members. He had been in recovery from a long term heroin

addiction for approximately ten months at the time he offered his services to the project. Working on the project and feeling useful helped to raise his confidence/self esteem and was a positive experience in further carrying him along the road to recovery.

Harry's comments:

'From within one of the centres I visited I have now joined a men's health committee. I didn't know this existed before I got involved in the project. I found it [the project] an interesting experience and have grown from it.'

Almost another year on and Harry is still in recovery and working voluntarily for two community projects within his local area. These organisations allow him to use his newly acquired skills from college courses he has recently completed.

The other two volunteers were white females with some previous research experience.

Like Harry, although from a different regional area, Hermione was also in recovery from a long term drug addiction when she offered help to the project. Hermione was very bright and able. Drug free she had a warm, friendly, and bubbly nature. As part of the project she visited a day care centre for people who were cognitively challenged. She sat with individuals at the centre and very patiently explained the questions on the questionnaire sheets, listening carefully and recording the comments they made. She also hand delivered and collected questionnaires from other community groups in her local area.

Hermione's comments:

'It was confidence building and it increased my understanding of communication skills. I also

became aware of more local services within the community and the difficulties they might encounter.'

Twelve months on and Hermione is still drug free, has completed a college course and various training courses. She has also been engaged in voluntary work within the community. Her education, her life experience and in some small part, her involvement in the project has not only enabled her to rejoin the paid workforce but to secure her a responsible position working with vulnerable people: a step she sees as the first rung in her career plan.

The third volunteer, Mrs. Weasley, was a friend and neighbour. She had completed a first class degree in social sciences some years ago. She had been involved in research within community housing and health, before moving on to work within the NHS. After a number of years of dedicated work fighting the corner of the disenfranchised she had come into conflict with the internal workings of a local organisation. This conflict was extremely damaging and was instrumental in contributing to her severe depression resulting in her being unable to work for a number of years.

On becoming aware of the project, she slowly became interested, but was not keen to be involved in the initial stages, i.e. piloting. However, with time, she became gripped with the issues of patient involvement and empowerment and began to employ her research skills. She researched the internet and made initial contact with a number of voluntary agencies throughout the North West, laying the groundwork, (informing people about the project), which allowed me to make follow up calls and arrange interviews and also questionnaire deliveries. This facilitated contact with

far more organisations than I could have reached single-handedly given the time constraints of a six month researcher's post. Because of her previous work within the NHS and community groups she was innovative in suggesting new contacts and signposting me to possible contacts within health and social care that I had not been aware of previously.

Mrs Weasley's comments:

'My previous experience had left me very disillusioned with concepts of the 'empowerment' and 'enablement' of individuals in the design and provision of services. I was reluctant to get involved, and only did so because I thought I was just helping a friend.

As I became more aware of the aim of the project it re awakened my interest in social issues and I have started to rebuild my faith in the belief that individuals and groups can make differences'

A year on and Mrs. Weasley is well into a Masters degree at the University. She has been on the 'Make Poverty History' protest in Edinburgh and although still struggling with depression, is beginning to develop some coping strategies to manage this debilitating condition.

Community Groups

Questionnaire distribution in some cases is simply a matter of handing over an agreed number of questionnaires to an organisation and waiting for returns, but on other occasions it is not a cold unattached process, but rather an opportunity to interact with community members directly. Many of these individuals were volunteers who had dedicated years working to improve the quality of life of their society members whilst also raising public awareness of the issues they face: for example, gaps in service provision, isolation for both patient and carer, lack of professional understanding of the day to day care, and in some cases lack of professional knowledge of the condition itself. Of the community groups I visited all are still in my memory as vibrant, innovative and needs led organisations. In the next section I would like to share my personal observations of some of the people I have met along the way.

One of the first places I visited was a voluntary drop in centre, open to all but is mainly used by South Asian groups. On arriving at the centre it appeared obvious that like many other voluntary organisations this one too was struggling financially, but despite that, I was inspired by the person in front of me. She was a woman with what we may still consider a number of social disadvantages i.e. female, Black and with mobility issues. Being passionate about her work, her negotiation skills were second to none. First she asked if I had any questionnaires that were translated into major Asian Languages. To my embarrassment, I had not considered the barrier that English as a second language could cause. She then offered a translation service at a fee for the centre. I walked away with the questionnaires

undelivered to consult with the team. Due to time restraints the team agreed that this oversight (of translation of the questionnaires) was not able to be rectified. However, being astute, she had offered me another solution. She could provide a team of bilingual volunteers to work alongside participants in exchange for a donation to the centre. This second option was agreed by the team so I went back to the centre the next day and was able to leave the questionnaires in her capable hands.

'Shaping the Future' was not only about reaching the elderly, the chronically ill, and minority ethnic groups but also about gaining the views of other socially excluded groups. With this in mind, and in order to be as inclusive as possible, I took some questionnaires along to a homeless shelter. This experience, too, has left a lasting impression. I have included this snap shot in the write up to illustrate this point.

The shelter had a neglected, or probably it would be more accurate to say, vandalized appearance from the outside. As I entered I was struck by the Dickensian character of the interior. The manager, however, who was a dominant, larger than life character, radiated warmth and commitment to her role. I was compelled to ask what made her decide to spend her days in such dismal surroundings: the residents may have had little choice but she was free to work elsewhere. Her answer was that there was a need, some one had to do it, and she could, so she did. Once again I was struck by the incongruity of the environment of many of the community groups and of the seemingly tireless generosity of spirit of the volunteers and workers within these environs. I felt both sad and grateful for the existence of this shelter.

Do No Harm

Whilst the primary aim of this research was to benefit individuals (both those accessing services and those providing a service) the ethical implications of research always throws up the possibility of damage to individuals. Indeed, much of the researcher's task is to minimize and manage the potential for harm. This was brought home to me the day I came face to face with the hurt research can cause.

On entering a community centre, the person I had arranged to meet had left early, so instead I was greeted by another worker from the centre. I explained the project to him and asked him if he would take the questionnaires for distribution. He said he would, and also offered to complete one himself as he believed he fitted the criteria of the target group. On reading the first page, 'satisfaction with health care' he suddenly became very angry and he said that I had intruded into his life by presenting him with personal questions that evoked painful memories for him about his experiences with health care. I had not expected this sudden reaction and felt a little intimidated. He said that I had caused him to feel upset and angry. He wanted to know how I intended to help him feel better. This seemed more of a threat than a question to me at the time. I thought for a moment and suggested that he contacted a patient advocacy service, but he just replied that he had tried the Patient Advocacy Liaison Service (PALS) but that for him, 'they were no use as they were in the pockets of the health care services'. I then remembered the fly sheet we had included with the questionnaire which gave contact details of other organizations where he could seek help and air his grievances. When I went through these options with him,

to my relief and surprise, this seemed to defuse the situation. He said that this was the information he had sought but did not know where to find it and by the end of our discussion he said that he felt better and actually thanked me for my help.

I left this centre with a better understanding of how research can impact on individuals, how a researcher must respect the unpredictability of a person's reactions and also of how vulnerable a researcher can be in some situations. As well as the ethical considerations of research, this incident highlighted the passion people feel about **their** services, plus the lasting pain of injustices left unaddressed.

In-depth Interviews

For this project it was decided that alongside the questionnaires we would conduct a small number of in-depth interviews with those accessing services and/or carers, from as wide a spread as possible across the North West. Recruiting such persons was not always easy. Nevertheless, I was fortunate in contacting some very helpful individuals and groups to name but a few; the Wigan & Leigh Carers Centre, the Motor Neurone Disease Society, the Huntington's Disease Association, the Stroke Association and an individual called Thelma who all equally welcomed me into their lives. All were keen to contribute to the project, with the hope that they could help to make a difference for themselves, and for others, in shaping the future of integrated health and social care services.

My initial contact with a Greater Manchester carers group was through a kind gentleman who worked at the centre. He arranged a number of carers for in-depth interviews, taking

into consideration the time restraints on both the carers and on the project. These interviews took place within the centre itself. I was made very welcome not only on my arrival but throughout my visit. A generous lunch was provided and refreshments were served during the afternoon. I was also introduced to the other workers in the centre who told me of their roles and explained the activities and support services they provided for the carers in their group. Indeed people could not have been kinder. I felt like a guest of honour. There was a real feeling of community strength within this group. They had a wealth of knowledge gained through experience of services, or in some cases lack of services, often having to be self reliant and innovative in their problem solving. The carers interviewed eloquently and passionately told their stories; I was filled with admiration and awe.

Further interviews were arranged through the individual societies. These took place in the homes of people accessing services, and/or carers, some of whom had been recently bereaved. These interviews were again very moving, evoking a full range of emotions from laughter to tears, sometimes shock, sometimes despair. I was again struck by the resilience and strength of these people and of their endless endeavours to work to raise awareness and to offer support to others.

Although meeting and sharing with these people was inspirational it also left me emotionally wounded on their behalf. It struck me that these were the people who held detailed knowledge of day to day care, but often they felt that this knowledge seemed not to be utilised, or indeed recognised by either health or social care professionals. Some had

expressed the view, and reported incidents where they felt that, they had not been treated respectfully by service providers. Gaps in service provision, poor communication, and lack of staff training were highlighted as the major factors of stress. On the other hand there were some who had a great deal of praise for the services they had received but they suggested that they felt they had been fortunate to fall within the right post code.

Finally, I would like to introduce Thelma as her story draws attention to the relationships that can develop between the researcher and the interviewee and in this specific case the extended family. Thelma was in her mid seventies, had multiple health problems and was terminally ill. Throughout the last year, she had been cared for primarily by her elderly brother (Ernest) who had returned to England from his home in Spain to live with her. I had arranged an interview with Linda, his daughter, who was currently offering respite care for her aunt. When I arrived at the house Linda introduced me to her aunt Thelma and excused herself as she was busy seeing the doctor out. Thelma invited me to come and sit on the bed and she began to tell me of her hospital care and her experience of 'health and social care' since returning home. I interrupted her and explained the reason for my visit and asked how she would feel about being interviewed instead of her niece Linda.

I offered her time to think about this but she said she would be really pleased to tell her story on tape and also said she would be proud to have her experiences written up. She was adamant that her story was important, needed to be told and was, therefore, keen to contribute. In accordance with ethical principles anonymity was assured, but Thelma

declined, expressing a wish for her name to be unaltered. Not wishing to be interrupted during her interview Thelma suggested that her niece take some time out to do the shopping.

After the interview had drawn to a close, the conversation turned to broader issues. Despite her frailty, she chose to talk positively and constructively about her impending death. Indeed she expressed her relief at being able to talk freely about it as she felt she could not broach the subject with her family. The conversation also turned to her childhood, her youth and the fashions of the 1940's including the dresses she had made, the dance halls she had frequented, and how beautiful she had been (I have recently learned that she once held the beauty title of Miss Preston). She reminisced about the happy times she had enjoyed through the different stages of her life. The clarity of thought and sense of humour expressed by Thelma made my visit a moving and memorable experience. And she reinforced my opinion that people's views and needs must be heard and respected.

Thelma died not long after this interview and her family invited me to her funeral. It was a privilege to attend and to witness the deep love and respect the family had for her. I only wish she could have heard the tributes paid to her. I have not changed Thelma's name – not only at her request but at the behest of her niece, Linda:

'don't change her name, she wouldn't have wanted that, call her Thelma.'

Linda contacted me recently to tell me that sadly, her father had died. She also was pleased to offer the following comment for inclusion in this report:

'Although Thelma's terminal illness was a longer process than we [the family] had expected, it gave us an opportunity for re-forging family relationships. I was able to relate to my father on a different level than before, a time which I am really grateful for.'

The services in place, both health care and social care were excellent. The range of care they provided allowed us to give what care we wanted – the family were there 100% of the time. The value of the services took a long time to be appreciated by Thelma and even longer to get Dad in a position of using them to support him in his support in the home. Indeed, although my father dedicated his time and caring to Thelma, it was out of love rather than primarily duty or need.'

All of the people I interviewed had their own moving stories to tell. I have drawn attention to only a few of them here just to give a flavour of the researcher experience working out in the field. I apologise to the people I have not mentioned who contributed to the project in this way but I hope they feel they are represented in these thumbnail accounts.

Dissemination of Information

The strength of this part of the project has been to gain the views of those accessing services and of carers. This includes identifying gaps in care provision and in staff training from the 'service user' perspective. In order to apply these findings and to effect an improvement of services, the concept of 'best/good practice', demands dissemination of information across a wide range of individuals and groups. Through conferences, and direct contact with other 'service user' projects, information gained through this

project continues to be fed back to health and social care professionals and appropriate university faculties. Not only do the findings need to be disseminated but the methodology used in this research will also be shared with other research individuals and groups through The North West User Research Advisory Group (NWURAG) and through the 'Shaping the Future' publications and conferences.

As standard ethical practice all research participants have been issued with contact details so that they can, if they wish, be given feedback on the project. As a final stage of the research experience 'Thank You' cards were sent to all interviewees and to community groups wherever possible.

Conclusion

Those accessing services and/or their carers are not a problem to be solved but are part of the solution to better service provision and professionalisation of integrated health and social care services. This research has found that many people are interested in being involved in the training and delivery of the services they receive. People have a specialised knowledge of how their condition impacts on their lives. They feel that their knowledge is often underutilised in the training and delivery of services. We should look for innovative ways in which we can engage with those accessing services, also looking at more specialised ways of enabling hard to reach vulnerable groups to participate in research and training processes.

I shall conclude how I began by acknowledging all the people who participated by generously contributing their time and expertise to Shaping the Future of Integrated Health and Social Care.

Chapter 3:

Project Findings

3.1 Data analysis

The theoretical background to the analytical techniques adopted in this project is a phenomenological one. As Thomas and Thomas (1928) suggested in their oft-cited quotation:

"If men (or women) define situations as real they are real in their consequences." **(my addition)**
(Thomas & Thomas 1928, pp. 571-572)

The point with respect to this study is that the 'truth' of a piece of information gleaned from an interview, for example, is not particularly important. This study sought to access people's perspectives on integrated health and social care and did not seek to make judgements on whether a report on these perspectives is a 'true' or 'valid' reflection of how participants see the world. Rather, this study sought to attain as authentic a representation as possible of people's accounts. The goal of the phenomenological perspective is:

"...description of the meaning of an experience from the perspective of those who have had that experience- that is, to describe the meaning of an experience from the worldview of those who have had that experience..." (Cohen and Omery, 1994, p.148).

Some proponents of this approach make ambitious claims for what it can achieve, in suggesting that such descriptive data can enable phenomenologists to "see the world as subjects see it." (Bogdan and Taylor, 1975, p.2). This is a naive and atheoretical claim, as we can never 'see' the world as others see it. We cannot hope to enter wholly into the perceptual world of another, but perhaps we can try to present or reproduce 'authentic experiences from the inside' (Walton and Madjar

1999, p.6).

In attempting to convey the thoughts of others to a wider audience it is important to acknowledge the role that the researcher plays in interpreting and translating those thoughts. The apparently straightforward representation of verbatim comments, for example, belies the complexity of the process that is involved in the analytical process:

"...there is a tendency to simplify the complex processes of representing the 'voices' of respondents as though these voices speak on their own.....rather than through the researcher who makes choices about how to interpret these voices and which transcript extracts to present as evidence." (Mauthner and Doucet 2003, p.418)

The use of the 'constant comparative method' of data analysis (Strauss and Corbin, 1990) attempts to mitigate the effects of researcher subjectivity by ensuring that different researchers independently read transcripts before deciding on key themes or categories. This analytical approach was employed within the present study in relation to transcripts of tape recorded focus groups, interviews and in the analysis of questionnaire text variables. It must still be noted, however, that the thematic analysis presented here cannot be regarded as a definitive interpretation of how participants perceived the issues of integrated health and social care. We believe the account presented below to be an authentic representation of our data but we must also assert that no 'reading' of research data can ever be accepted as the complete and final answer.

3.2 Focus group findings

As mentioned earlier three focus groups were conducted, all of which

were tape recorded. Only two of the group discussions were possible to transcribe, as there were difficulties with recording equipment in the third group. Thus, although this section was informed by notes from the third group there are no verbatim comments from this focus group. Direct quotations are drawn from both the focus group with carers of people with Huntington's Disease and the group made up of carers of young people with learning disabilities. The key themes which emerged from the analysis are set out below.

3.2.1 Working together

The issue of working together represented a prominent theme within the focus group discussions. It arose as a direct response to broad questions posed by the focus group moderators, but also in dialogues between group members. Comments on this topic amongst group members were largely negative. One participant was apparently already concerned about the quality of services received, and felt that the advent of integrated care may lead to more difficulties:

"Now there's this sort of working together thing now, health, social and education, so they're gonna get more unruly!"

Another participant indicated reluctance to be involved in the debate about health and social care integration – particularly with respect to funding:

"It's not that I'm disinterested about where [name of person]'s funding comes from but..... why should we even have to have a debate on where the money comes from? Make the decision, central government! Is it a health issue or is it a social care issue, for all of us so that we know who we have to go to."

Effective communication between different workers involved in care provision is obviously a cornerstone of integrated working. Concern was expressed about lack of communication between health professionals and home care staff in this respect, which ultimately led to failings in the care provided:

"Whilst we would have the meetings with the therapists...the experts... and we would agree a way forward to address particular issues or problems, that never was cascaded through the people in the frontline – the carer. And it was important because there was changes in how you might deal with a certain situation or accommodate a certain situation... the carers were the people that have to put that into practice."

Home care staff were the subject of much concern within the focus groups, but also in the data provided through questionnaires and interviews. Whilst the above quote suggests a possible lack of commitment in passing on information to home care agency staff, the next implies a lack of commitment on the part of the agency staff themselves:

"We had a review about a month ago and they were asked to go to the review and not one of them turned up and therefore I've just put it to them as a matter of fact, because [name of person]'s got behavioural problems at the moment. I said if anything happens...while she's in your care I says you wouldn't know how to go about it,"

Indeed, the sense given by discussions within these focus groups was one of 'disintegrated' rather than integrated care:

"Its like you've got so many people, because you've got your community nurse, you've got your district nurse and I had a meeting at [name of place], one was saying one thing and nobody knew what was going on because there's so many people involved in his care"

It was interesting to note that people had found ways to enhance integrated working through their own interventions, as in this description of a woman's efforts to ensure that her son received satisfactory care in hospital:

"we had a care plan that...went everywhere with....all his 'non negotiables':. you know, 'he can't have his milk and he's got to sleep on this side...'. But when he actually went in hospital obviously then the nurses, no way they could sit down and read this thick...so what we did in the end we took...some sheets out that was absolutely essential: 'he has to have his food liquidised and he has to sleep on this side and he doesn't have milk'. And we put about four at the top of the bed."

This seemed like a very pragmatic approach to the issue of partnership working. The participant above showed a good understanding of the working culture of nurses (i.e. very limited time to spend with each patient) and used that understanding in such a way as to provide the greatest opportunity for the client's needs to be met. Health professionals appear to have much to learn from people who care for vulnerable relatives on a day to day basis:

"When [name of person] was in hospital and I was feeding him...they were actually watching the way I fed him and they found it better to watch the way I was feeding him to pick up on"

3.2.2 Training

The training of health and social care workers was highlighted within the focus group discussions by this last remark. It was interesting to see that training was an issue that was brought up spontaneously without necessarily being prompted by the moderator. In one of the focus groups participants had been actively involved in training for a number of years, and suggested an innovative way of introducing workers to the cultural world they inhabited:

"When we do our training session we're giving one demonstration which is two clocks on a wall – one has fingers on it and the other hasn't. The one with fingers is the professional clock, the one without fingers is the carer's clock, because there's not such a thing as 24 hours in the life of the carer: It's 7 days a week, 365 days."

Within this focus group it was implied that services needed to become much more user centred. Participants commented upon the importance of early training on the needs of clients and carers and emphasised the need for such training to involve all levels of health and social care workers:

"Participant A: You need to be with the students don't you [name of person]... you need to be in there before they start getting set ways of doing things. You need to get in pretty quick."

Participant B: And if you are doing things just don't solely do it with the nurses ask for the doctors and the consultants and the admin staff"

In the same group a few of the participants set out quite clearly the skills that they felt health and social care workers required to be able to meet the needs of their relatives:

"Interviewer: *If you had 5 minutes with a group of health and social care workers what would you tell them that they needed to know?*

Participant A: *They need to be more highly skilled, the skills are definitely lacking.*

Participant B: *First and foremost there's listening to what the carer's saying.*

Participant A: *And act on it, don't just listen...*

Participant A: *Feeding skills.*

Participant B: *Training skills.*

Participant C: *Walking, handling skills.*

Participant B: *Communication Skills...*

Participant A: *Well it's no good giving them the skills if they've not got the time. They've still got to understand – the bosses I'm talking about, not the nurses. Because the nurses try, but they just can't do it with the time they've got."*

Again, the importance of training across all grades of health and social care workers was suggested to be essential. Such comments implied a lack of managerial commitment to training of the workforce.

3.2.3 Home care

The quality of home care services is evidently something which is very important to people who often rely heavily on formal support provided in the home setting. Both lack of continuity in the care provided and lack of training for staff were significant themes. Different members of staff coming in and out of a person's life appeared to present some very real difficulties:

"Participant F: *Lack of continuity – lack of consistency in the level of service, consistency in the same people coming in.*

Participant G: *It is key for the majority of Huntington's sufferers that there is that continuity there because of the cognitive difficulties that they have in dealing with change"*

Lack of specialist knowledge amongst home care staff about medical conditions was suggested to be a problem in terms of workers' ability to offer appropriate care:

"You can only manage them (cognitive difficulties) if you understand what you're dealing with. And again that's another key area, there was just lack of knowledge and understanding. Now it might have been at the psychiatrist's level but that's not cascaded again down to the level of care."

As will be seen later (in the analysis of questionnaires and interviews) good communication skills were considered to be a key issue of concern. Such skills were often judged by participants to be lacking amongst frontline workers. Good practice in this respect was also acknowledged however:

"I've recently been at Crossroads and they've come and interviewed me... they wanted to know where all the power points were, they wanted to know where the water were. I said what d'you want to know all this for... and I thought it was excellent... They've got time for you, Crossroads, they don't just rush out or whatever. If you've got anything to say or anything like that, they'll stay, listen"

The importance of active listening skills was a recurrent theme within the discourses of both carers and service users. Participants' accounts suggested a dearth of workers who were available to sit and listen to their concerns. Whilst lack of time is obviously a factor which often lies beyond the control of individual

workers, this aspect of care seems an important issue to acknowledge in the lives of people using services.

3.2.4 Fighting

Participants seemed to be frustrated at the amount of 'fighting' that they believed they had to do to secure services. This is evidently an impression gained from a small number of people, but there were consistent remarks about 'struggling' for help, as opposed to having needs assessed and related services provided:

"You're actually fighting all the time for services aren't you: fight, fight, fight!"

Again, the issue of limited resources must be taken into account, but it seems rather contrary to notions of 'patient-centredness' that people in an already stressful situation should have to struggle to obtain services to which they may be entitled:

"Participant A: *You have to fight...and you have to ... go into the service itself and to really make yourself unpopular... The one who shouts the loudest gets the best service.*

Participant B: *And it shouldn't be like that...because sometimes you'd feel you was a moaning parent and get yourself a reputation*

Participant C: *And then if you worry a lot you'd be frightened you have the service taken away."*

Indeed, there seemed to be genuine concern about the reputation that one might build up with services because of regular complaints:

"Well I just call myself the dragon because you end up, you feel as though you're a dragon because you're moaning and groaning at different things. You feel the person you were you're not anymore."

3.2.5 Good practice in service provision

Fortunately, there were many comments about service provision which were positive. The importance of having a good social worker was emphasised; particularly where the social worker could act as an advocate. One woman suggested that she had had 'some good social workers', and emphasised:

"How important it is to have somebody at the helm who is committed. Because that social worker, there wasn't enough she could do. She was very proactive"

The staff of one residential care home came in for particular praise:

"Participant: My sister was in the same unit... she was there for 8 and a half years. She had her moments but they coped and were very very good."

Interviewer: And you were quite happy with the quality of care that she received?

Participant: She couldn't have been in a better place."

The importance of being a member of a support group was also mentioned:

"nice to know that you get the support of an organisation like this. At this local branch we've known each other all now for 13/14 years... they're the people I trust."

As mentioned earlier workers' listening skills were accorded much significance, but so also was the ability to act upon the advice given by a service user or carer. The notion of advocacy is again significant in this respect, as is the concept of empowerment:

"If your doctor listens to you that's a start and you know that he's understanding. My doctor would listen but he left the decision to me."

If I said he (person being cared for) needed hospital, he needed hospital. He phones them straight away – 'take him!'.....I was happy with them letting me make the decision."

Health professionals appeared to gain particular respect from carers when they took extra trouble to meet or investigate the needs of people being cared for:

"Participant A: She (GP) was lovely. This is a good incident – the last time he had a medical with her, because she used to give him a full medical, I had to go to the surgery...and I mean John, he gets out of his chair and he just lies flat on the floor. You see that's his way of saying I'm not doing anything... So there she is with a stethoscope round her neck and John's crawling round and she's at the back of him. it was difficult trying to listen to his chest but... she said they don't learn us this in medical school!..."

Participant B: She was a brilliant support

Participant A: She understood

Participant C: And she asked you the questions that you wanted to be asked."

Securing sufficient practical and emotional support came across as issues of central importance to the lives of carers. Effective advocacy appears to be a key means of achieving this objective:

"when you think of the stressful situations that the carers are in, you know quite emotional as well at times, they need a voice don't they?, They need somebody to go into their office to their managers and say now, 'look!', and lay it down."

3.3 Questionnaire findings

3.3.1 Introduction

The questionnaire opened with an introductory section which focused, firstly, upon participants' satisfaction with health care services and, secondly, with their satisfaction with the range of social care services they had accessed (see Appendix 6). A variety of differing forms of health and social care were listed and people were asked to rate their level of satisfaction with each aspect of care. A series of subsequent open questions allowed them to elaborate on the simple, quantitative responses. This section helped to establish in people's minds the types of service which could be defined as health and social care. We felt that this was a useful prelude to the more complex topic of integrated care.

The questionnaire also focused upon the following areas:

- Experiences/general views on partnership working in health and social care;
- Perceived effectiveness of hospital discharge services;
- Views on training of current health and social care workforce;
- Experience of students within health and social care;
- Perspectives on training of the future workforce;
- Service user involvement in training.

The questionnaire was semi-structured throughout with significant space left for participants to write down their thoughts in addition to responding to pre-set closed questions. As with the rest of the methods used the objective was to attain as authentic a representation of perspectives as possible.

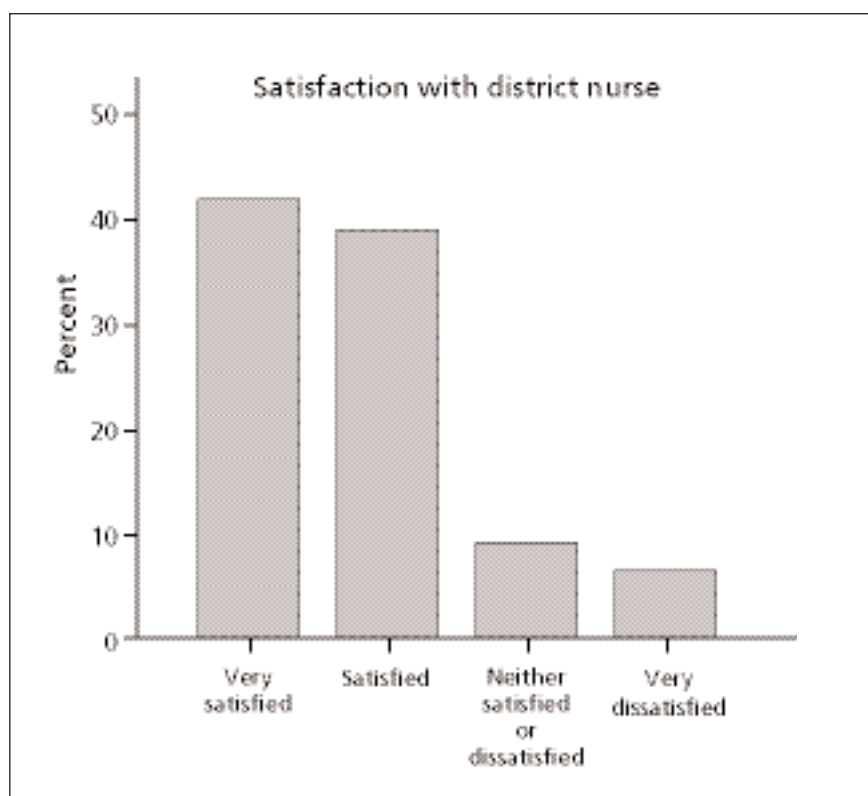
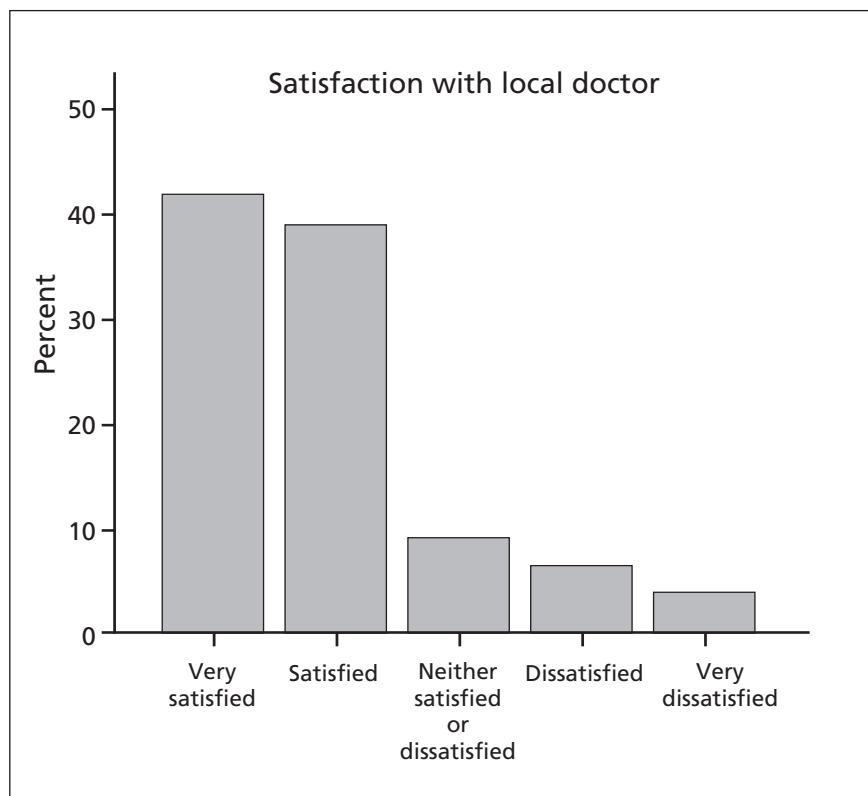
SPSS for Windows Version 12 was used as the main vehicle for analysing the quantitative variables. The SPSS analysis was restricted to simple use of descriptive statistics; that is, frequencies. Closed question responses were entered into an SPSS database, whilst text responses were subject to a thematic analysis. Verbatim comments are used here to illustrate the various themes which emerged from the textual data and to give further insight into the limited responses to closed questions.

One hundred and twenty six questionnaires were completed and returned. Of these, sixty four were completed by people who described themselves as 'receiving help from health and social care' and sixty one as 'a carer of someone who is receiving help from health and social care' (one participant didn't give a response to this question about their status). Although Chi Square analyses were conducted, no significant differences were found between the perspectives of carers and direct users of services with respect to any variable.

3.3.2 General views on services provided

In response to the general ratings scales concerning the various forms of health care, reported levels of satisfaction were high. Satisfaction ratings appeared to be particularly high in relation to services provided by the local GP.

Satisfaction also seemed to be high concerning services offered by District Nurses.



General comments about the services offered by District Nurses were positive with regard to the role they played in home care. People often seemed to find the District Nurse to be an invaluable form of support:

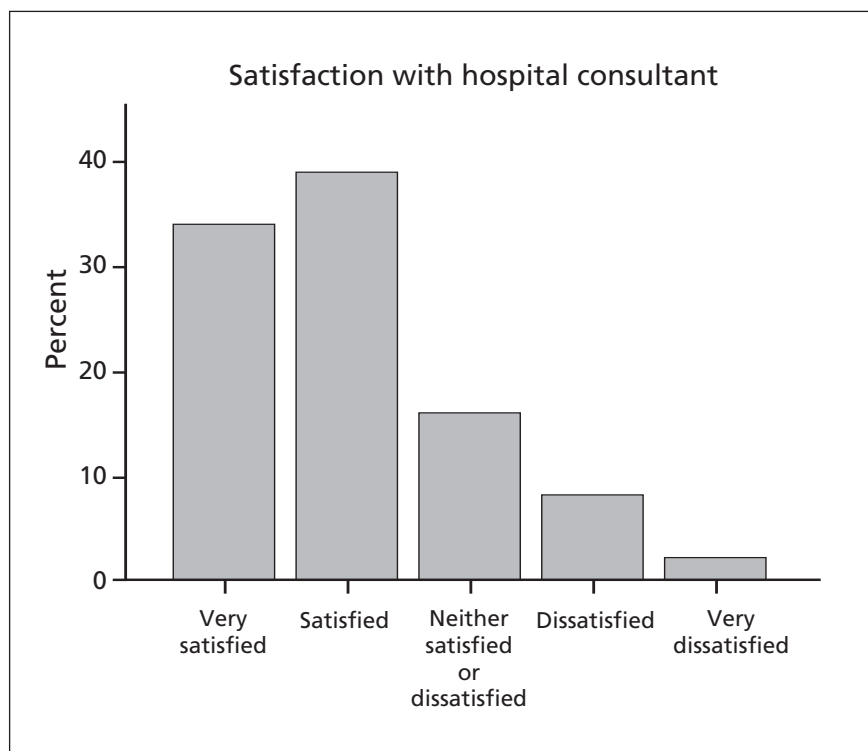
"I couldn't fault the District Nurses. They were wonderful. They'd nip in and say, you know, 'we've just come to see how you are', and if they had time they'd sit and have a drink and talk to John."

As in the focus groups the theme of active listening came up again here, with workers who took the time to 'listen' gaining particular respect. High levels of satisfaction were also reported with regard to assessments of the service provided by Hospital Consultants.

Results concerning health care services were not, however, unequivocally positive. Views on the effectiveness of hospital discharge services seemed to be more mixed than those for the services offered by individual health professionals. Of the 63 people who gave an opinion, 29 rated the discharge communication as 'good' or 'very good', 19 as 'average', and 15 as 'poor' or 'very poor'. The focus groups had suggested this may be an area of concern for service users and carers alike. Thus, we took the opportunity to explore participants' views on these arrangements in some detail in the questionnaire.

Many participants were pleased with the discharge service that they or their relative had received:

"Social Worker attended the ward round and in my presence my care was discussed with me – Social Worker took me home when I was discharged".



"When my wife was discharged from hospital all day care was provided from day one. Care was greatly appreciated."

As the figures above suggest, however, there were also a number of participants who reported being unhappy with the discharge services they had encountered. Accounts included some apparently serious failings in the hospital to home care transition:

"When I was discharged from hospital the staff did not inform my home carers that I was being discharged. So I didn't have any home care for two days."

"Discharged from hospital in such a 'pass the parcel' way and with no communication between hospital staff and care home staff. Will never return to hospital. Lack of professionalism=lack of care."

Ratings were high for the care

provided by Social Workers, but were more equivocal in the case of Hospital Social Workers. Although there was no verbatim data available to help interpret this finding it may have been related to the relatively ambivalent feelings displayed towards discharge procedures, given the central role that Hospital Social Workers play in this process.

Positive comments concerning the role of Social Workers centred on their success in co-ordinating the provision of care packages that met the needs of people or their carers:

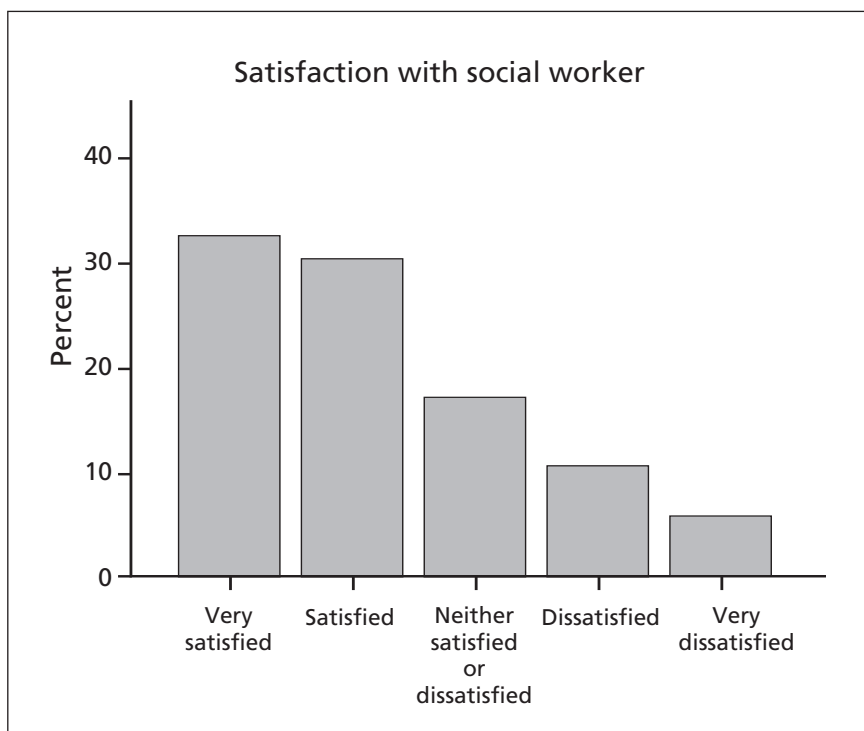
"All the Social Workers were really helpful in arranging care for my husband."

Participants seemed particularly impressed when the Social Worker appeared to go out of his or her way to help out:

"Excellent Approved Social Worker who deals with my care immediately when I'm in crisis. ASW has stayed with me hours after she should have finished work."

"The Social Worker listened and took into account both our needs"

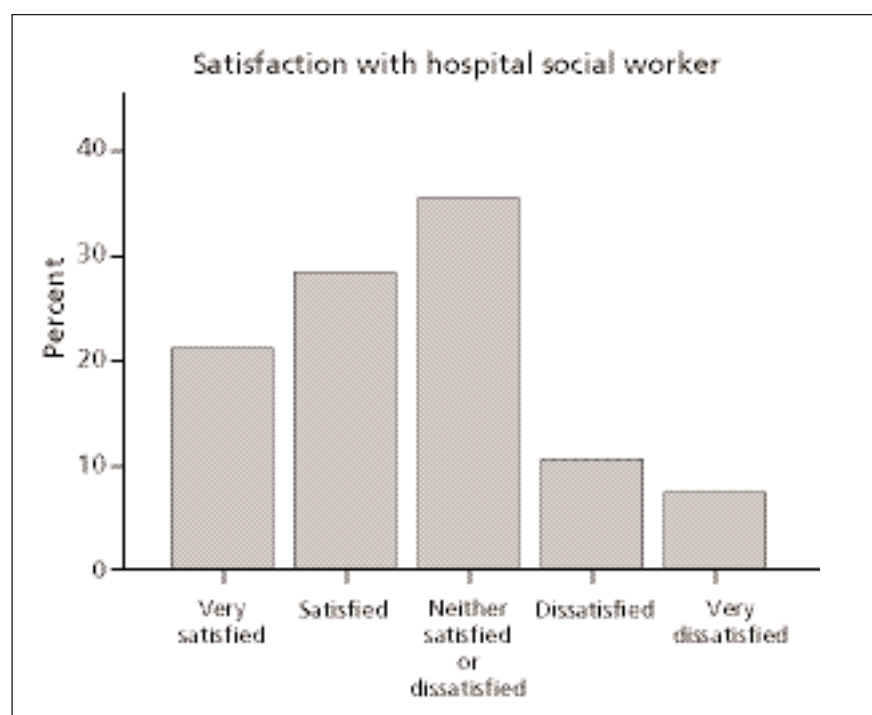
Where there were complaints about Social Workers concern was expressed particularly about workers who were seen as failing to live up to perceived expectations of a Social Worker's role:

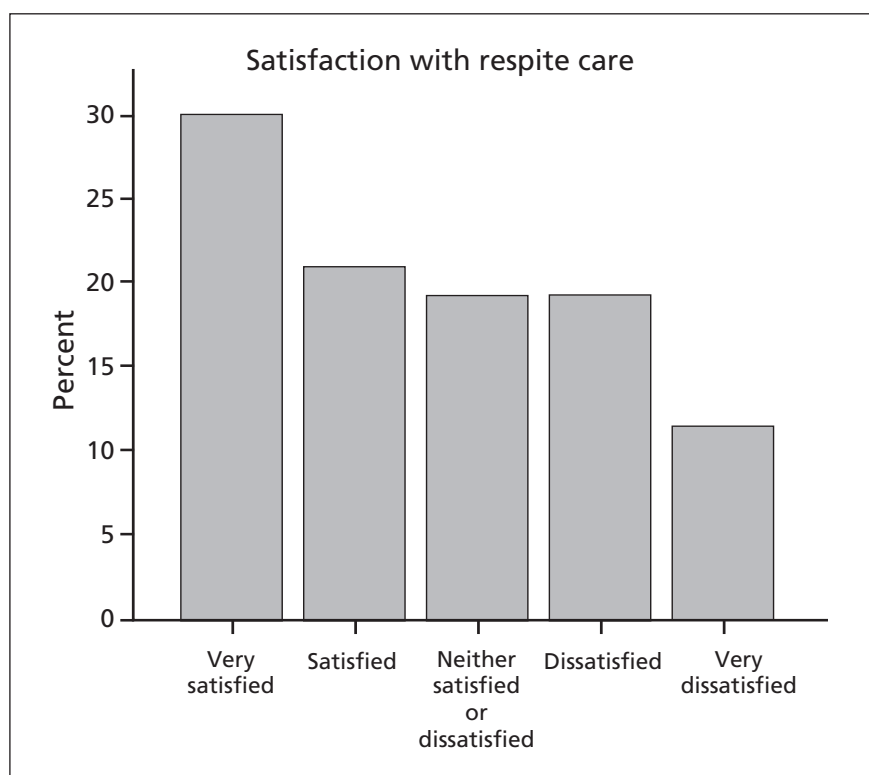


"A Social Worker should fight for the client. Some take the status quo – shrug shoulders, don't rock the boat: need to be assertive for family who are already burdened."

As with the focus group discussions, advocacy appeared as a significant theme within both questionnaire responses and interview transcripts.

Views on respite care were also somewhat equivocal. There was quite a wide distribution of views across the range of satisfaction ratings. Of the 60 people who responded to this particular question, 31 were either 'satisfied' or 'very satisfied' with the respite care they had been offered, with 11 being 'neither satisfied or dissatisfied', and 18 either 'dissatisfied' or 'very dissatisfied'.





Most of the complaints about respite care concerned the lack of respite care facilities. Difficulties in securing respite care were mentioned, with one participant suggesting that getting hold of respite care was something of a 'post code lottery'. Within the in-depth interviews a carer gave an eloquent description of both the difficulties of securing respite care and the associated implications of not receiving it. His wife was suffering from Multiple Sclerosis:

"...in October I requested, through my Social Worker, cover for my wife for a weekend in December while I went away...Now bear in mind its not just me going away for weekends: when I go away with my group, for example, I'm the coach driver as well. So if I don't go, 16 other people don't go. I've got to go if you know what I'm saying and I requested this in October through the Social Worker, who then reported

back to me and said, 'they say it's okay, it'll be fine'. So at the beginning of November I checked with them and said, 'is everything still okay'? He said, 'oh yeah it's not a problem'. So okay, fine. At the end of November I checked with them again to see if they'd actually sorted it out: "No we've not sorted it out yet, but it's alright don't worry about it, we'll cover it". Two weeks before I was due to go they faxed the Social Worker with a note that said, I'm sorry we can't provide that weekend now. We've got too many staff off sick."

3.3.3 Experience of students

The training of health and social care workers was addressed within the questionnaire as well as within focus groups and interviews. The related item within the questionnaire asked firstly whether participants had had any experience of their care being provided by students. Thirty four participants were certain that their

care had been delivered by a student in training at some point, and twenty six were not sure whether students had been involved in the provision of their care. The rest were sure that students had not been involved in their care.

A follow up question asked for participants' views on the help provided by students. The majority of comments made were positive:

"All students need practical experience, otherwise they won't gain all the knowledge. The (podiatry) student was a bit apprehensive but did well... The student who was counselling was very good, and I hope that she is now qualified, because she would be an excellent counsellor"

"Students regularly 'sit in' on consultations and some have carried out examinations with my permission."

"I don't mind a student doctor sitting in – it helps with training."

"At the nursing home the student was extremely nice...helpful and... keen."

One participant suggested that the care provided by student mental health nurses was more satisfactory than that offered by their trained counterparts:

"They were supposed to be training but gave better assistance than the other qualified nurses sometimes."

"Students were nicer and more willing to learn, and had more time for you."

As in the other research encounters the training of home care workers was brought into question:

"(They) send newly employed youngsters with no training and no idea of what to expect. The fact that

my wife is an intelligent person who is able to instruct them is their only help."

Two participants were unhappy at having students present at consultations with health professionals. In the first case the person's account suggests that the nurse at the local health centre had not sought permission from the patient for a student to be present. And in the second, the person felt under pressure to agree to a student being present:

"not introduced as a student – just watched throughout. As a result I was uncomfortable."

"Felt obliged to say yes to having them there but put off by them being there."

Obviously, people do not hold simple one-dimensional views on such issues. A student nurse on a dementia ward, for example, was described as being "quite caring and sympathetic", whilst a student nurse on an Accident and Emergency department was said to be "slap dash and did not show sympathy for (the) dementia patient".

3.3.4 Training of workers

Participants were also asked to judge whether they thought health and social care workers had been well trained to provide either their own care or that of the person they were caring for. Of the one hundred and fourteen people who responded to this question 51% thought that health and social care workers had been well trained, 34% thought that they hadn't, and 15% were unsure.

The subsequent open question asked for ideas about the ways in which the training of health and social care workers could be improved. Many of the comments here focused again on perceived inadequacies concerning the training of home care workers.



There were a variety of suggestions as to how home care workers' training could be enhanced; for example, by reinforcing the need to show 'respect':

*"Foundation course before letting loose on public – how to behave in people's **own** homes – dress code, basic principles of hygiene, manners..."*

"Stressing the importance of hygiene and, silly as it may seem, wiping their feet, well, when entering a person's home."

A key theme was the need to ensure that home care workers were trained sufficiently concerning basic communication skills:

"Doubt if home care agency staff had any training! Train to listen to and respect wishes of clients. Training in empathy."

Most participants seemed to interpret the question primarily with reference

to the training of home care agency workers and some interesting suggestions were put forward in relation to improvements:

"I answer this as a former association visitor for Motor Neurone Disease (MND)...It is not possible or economically feasible for social care workers to be trained to cope with MND. Suggest modern IT be used to give information on handling MND patients – a website to refer to and print off from for those workers who come into contact with MND."

Such suggestions echo the earlier focus group discussion concerning workers' perceived lack of knowledge about clients' health problems. This reinforces the impression throughout the study that home care workers may be ill prepared to meet some of the key challenges that they encounter within their daily work. This seems especially significant given the central role that such workers could play in the integration of

services; and given that they are perhaps the most public face of 'integrated' health and social care.

With regard to the wider health and social care workforce accounts emphasised the importance of utilising the skills of service users and carers in training:

"Involve patients and carers in the training. Not just as a token gesture, but as a valued (financial) contribution."

"By getting people who have used services to train them, recruit them and manage them."

A few participants were either aware of, or had had involvement in a user led initiative based at the University of Salford ('Citizens as Trainers'). It was suggested that a way forward for training was:

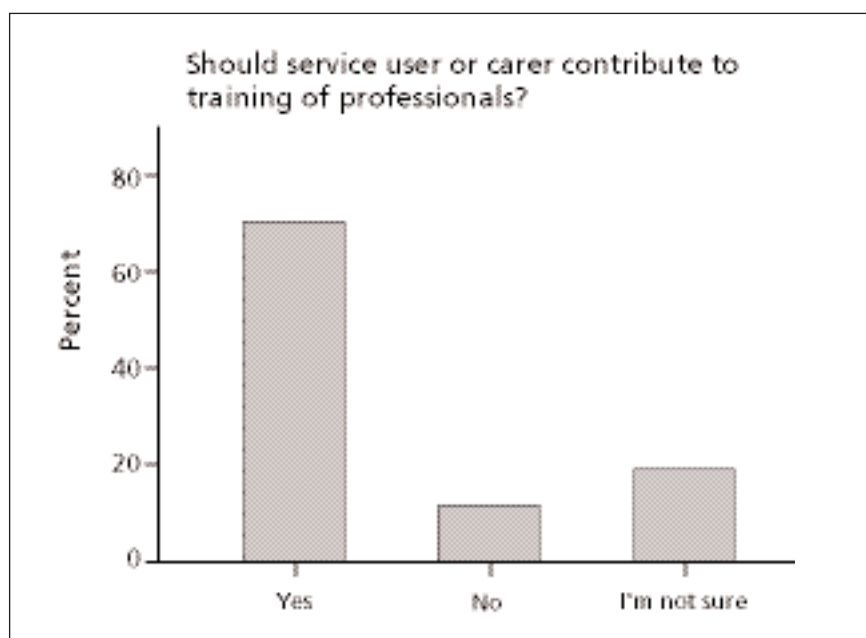
"To have more service user involvement, like CATS based at Salford University, who teach the students doing the Social Work courses."

"Listening to CATS (Citizens as Trainers) – experiences which should help them become better social care workers."

The integration of services, or apparent lack of it, was alluded to in the comments of a couple of participants, with the suggestion that any training needed to focus on enhancing interdisciplinary working:

"Let the left hand know what the right hand is doing. In other words get them together."

Such perspectives seemed to be based on experiences of 'disintegrated' care.



Again, suggested improvements in training seemed to come down to what would appear to be fairly straightforward, if apparently elusive principles to attain in terms of service provision. Overall, it seemed often to be quite crucial character traits which were judged to be missing and which needed to be developed in the training of health and social care workers:

"They need to be more caring."

3.3.5 Involving people who use services in training

Participants were also asked whether they felt that they themselves should be involved in the training of health and social care workers. In view of the comments outlined above it was not surprising to see that both direct users of services and carers were very keen to be involved in the training of the health and social care workforce.

Forty four percent of participants thought talking to the trainers in charge of training programmes would be a good idea, whilst forty six percent thought attending training

sessions to work with trainees and students would be a good idea. Thirty nine percent thought taking part in committees to develop better services would be a good idea.

Verbatim comments on this topic focused largely on the role of carers as 'experts', and the utilisation of their knowledge in the training of new workers:

"The students should be given the chance to have some time with the carers to learn about the way of caring for the patients."

"what you need is 'real' person input rather than a trainer telling student what they think an individual needs."

"I feel after five years of caring that trainers should listen to us – we are experts."

Other suggestions included service users and carers being on interview panels for the appointment of health and social care staff. At least one participant had already been involved in this way. A number of participants suggested that they would like to use their own experiences as case studies

to contextualize students' training. Enthusiasm for user involvement in training was apparent throughout people's accounts:

"Involving people would only improve the services at all levels"

Of the small number of people who were not keen on being involved in training reasons given included: lack of spare time because of caring responsibilities; feeling 'too old' to take on such new initiatives; and a general feeling that training should be the responsibility of health and social care professionals 'who should know how to train'.

3.3.6 Partnership working

We had anticipated that only a small number of participants would be aware of joint arrangements concerning service provision. A significant proportion of the 112 people who responded to this question, however, (44%) suggested that they had had experience of partnership working with regard to their own, or their relative's care.

Participants who responded in the affirmative were asked to describe the types of partnership working which they had experienced. A variety of differing partnerships were outlined:

- Social Worker and Home Carer;
- Social Worker, Nurse and Hospital Consultant;
- Support Workers, Social Worker and Hospital Consultant;
- Community Psychiatric Nurse (CPN), GP and Hospital Consultant;
- Social Worker and CPN;
- A Men's Health project partnership between Primary Care Trust and Social Services (Social Care Support Workers and Nurses working in partnership);
- Nurses and Social Care Support



Workers at Day Service;

- Hospital Nurse, Dietician, Social Services Day Centre staff;
- Social Worker, OT and Physiotherapist (described by the participant as part of the local 'Integrated Care Team');
- Ward Sister and Social Worker;
- Health Visitor, Social Worker and hospital Sister;
- Social Worker and District Nurse;
- Age Concern, Crossroads, Health Visitor;
- Psychiatrist and Social Worker;
- Social Worker and Occupational Therapist.

The make-up of a health and social care partnership obviously depends on the specific care needs of the individual. There was clear evidence here, however, of a variety of partnership working arrangements, some of which seemed to take place within a clearly formulated strategic approach to integrated care; for example, under the auspices of an 'Integrated Care Team'. Partnerships

between statutory and non-statutory workers were also described.

Participants who had had experience of partnership working were asked to rate the effectiveness of partnerships. Many participants suggested that the partnerships had worked well. The opportunity to obtain verbatim comments here was also useful in helping to shed further light on the nature of partnerships:

"My husband attends day care weekly and the therapist, consultants and nursing staff have discussed his care."

"Health and care worker worked alongside each other in the Intermediate Care Centre."

"I didn't see both of them together, but the District Nurse referred me by phone to the Occupational Therapist, who responded to a quick visit, and arranged what Social Services I required very quickly."

Integrated services seemed to be in evidence both in terms of the organisation of community services, but also with respect to hospital

discharge:

"I was in hospital on three separate occasions – angina was diagnosed. Age concern helped with shopping and advice on my release. They were really good, helpful and kind."

Integrated health and social care was praised for different professionals' abilities to communicate with each other and agree common goals, and also to communicate issues concerning care planning to home care support workers:

"All knew what each were doing – weren't pulling against each other. This was then brought to the support workers."

Many positive comments were made about the overall effects of integrated services:

"Full of praise for all of them."

"They were very supportive."

"Always very caring."

Such positive comments were almost equally balanced, however, by comments which suggested that care could often be uncoordinated:

"Didn't always follow the plan made or long delays. Several staff changes – lack of communication...As an ex-carer communication seems to be poor between health and social services. Even a bit of 'it's not our concern'."

The same person was, however, also keen to make this point:

"Please know that some workers are exceptionally good."

The 'not our concern' narrative was also reproduced in the account of another participant who suggested that different services' abdication of responsibility had left her in a very difficult situation:

"My husband's hoist broke down on

Saturday. After lots of telephone calls it was Tuesday before I got any kind of help. NHS say not responsible – so did Social Services. The hoist is my lifeline."

The same participant took part in the subsequent in-depth interviews and elaborated on this experience in more detail:

"I rang the duty Social Worker and... 'nothing we could do'. I rang another Social Worker and she said, 'get in touch with the District Nurse'. So I did, and the District Nurse said, 'are the care girls using that hoist?'. I said, 'yes'. 'Then that isn't our problem, it's Social Services'. So I got back to Social Services. A man came down and looked at it and said, 'I just can't get the spares, the hoist is obsolete'. But they did work well – the men themselves. Went up to [name of place] and tried to get spares."

The woman apparently managed to get her hoist repaired, but not without a protracted struggle. In addition to indicating the problems of disintegrated service provision, this account illustrates the earlier point about fighting for services. Support in crisis situations did not seem to be easily available, and seemed to involve much stressful work on the part of already burdened individuals. One participant perceived complaining to be a necessary step in arranging integrated services:

"...meetings were only arranged if we made a complaint re. quality of service provided."

As in the focus groups lack of communication between workers was portrayed as a very significant barrier to integrated health and social care:

"In my past experience there was no communication between the Health & Social Services."

"Social Workers and care workers don't always communicate."

"Often there is a lack of communication across the different services which can result in a breakdown in care."

3.3.7 Integrated care planning

Only thirty four people (31%) apparently knew that health and social workers met together to plan their care. These seem to be rather low figures given the importance placed on partnership working in current policy documentation, and the significance attributed to service users as active members of such 'partnerships'.

Where participants mentioned that they did know that workers met to discuss care plans, they suggested that the effect on the quality of care was generally beneficial:

"It has improved the quality of care that I receive."

"They each know what's going on, know what's involved. Can work different ideas out to make it better."

"Positively. Care plans are agreed and can be carried out together."

Occasionally participants seemed sceptical about whether such joint working arrangements would be maintained:

"Improves the care if they all continue to work together after care plan is devised – 'communicate'."

One participant's account suggested previous experience of uncoordinated care:

"Different people involved in client care should all know what each other are doing and planning. Can't stress this enough..." (underlined by person who completed questionnaire)

Some further critical comments on partnership working were made:

*"The **LEFT HAND** doesn't know what the **RIGHT HAND** is doing."*
(participant's underlining and capitals)

"Nobody plans care. My last care review for my son was 2001 and even then the recommendations were not implemented and we were never given an explanation".

3.3.8 Hospital discharge

Discharge from hospital to community care was an issue raised in focus groups and one that we believed to be an important aspect of integrated health and social care; albeit one that has received very little attention in the 'integration' literature. Sixty three percent of those completing the questionnaire had either been admitted to hospital, or had a relative admitted to hospital whilst receiving home care. Participants were asked how well hospital discharge staff communicated with the health and social care workers who were involved in their home care.

Positive comments were made concerning the help that was given by hospital staff in locating a care home when needed. Positive comments were also made concerning the role that hospital staff had played in providing information about, or making contact with home care agencies. Less positive comments were made about apparent lack of consideration by discharge staff about the arrangements that would be in place at home for people with high dependency needs:

"Didn't plan anything even to seeing if care would be in place on return"

A lack of professional 'caring' was again identified as an area of concern for participants:

"When a new health situation happens to either the carer or cared for, no-one ever asks whether the

carer can continue to cope with yet another health problem."

The accounts of many service users and carers within this study seem to suggest a lack of proactive work on the part of some health and social care professionals. The occupational culture portrayed often appeared as rather reactive and crisis driven.

3.3.9 Care notes

Within the focus groups, the idea of workers leaving care 'notes' in people's homes was suggested to be a useful means of enhancing continuity of care. This practice was explored further in the questionnaire stage by asking participants whether they had had any of these notes, and if they had, by asking for their assessment of the impact on quality of care. Of the one hundred and four people who responded, over half (54) had had such notes left with them in their home.

The use of notes was suggested to be particularly beneficial when community nursing staff had used them to pass on information to each other:

"Good communication achieved between District Nurses. Photos taken of pressure sores and left for other nurses to assess healing progress."

"The next nurse was able to refer to exact treatment advised on last visit to see if effective."

Notes were mentioned as being particularly useful where people had problems with memory and cognitive impairment:

"They (Home Carers) do read it when they come. Also Social Worker/OT/Physio can read the notes and know what's been happening – sometimes I've forgotten."

"Improved the service. It helps staff to communicate with each other. I have had a stroke and I don't always communicate effectively – verbally & written (I have had support from staff working for Social Services to write this)."

Concern was voiced about the extent to which care notes were read by home care agency workers:

"For those who bother to read the notes it saves time and patience in not having to repeat everything. In seven weeks we had seven different care workers each needing to be talked through the routine."

"When they read them it's been very helpful."

One person suggested that health and social care workers may hold different attitudes to the use of such notes:

"For Nurses good, gives excellent continuity. For Home Care...a waste of time. The carers have never referred to the notes and do not know what the (poor) notes contain."

The majority of comments about the impact of care notes were largely positive though, both in relation to their use by social care and health workers respectively:

"Gives a consistent service, and enables communication between carers, client, spouse."

"My home help can pick up the notes and read them and it will let them

know what they need to do so I get the exact care I need."

"There is a documented history of day to day care given and care needs required. And if problems are starting action can be taken."

Most people who had not had experience of such notes were enthusiastic about the possibility of such notes being used in the future. One participant was especially interested in the possibility of verifying the authenticity of the information that was being recorded:

"I would know what is being written and whether the information is correct or incorrect."

3.4 Interview themes

Ten in-depth interviews were conducted. Although fifteen interviews had been the target the time required to organise them meant that only ten could be completed in the time available. Eight interviews were conducted with carers and two with direct users of services. Interviews were tape recorded with participants' consent.

Much of the discussion served to elaborate upon, and develop several of the themes already presented in the focus group and questionnaire data. The opportunity for participants to talk at length, though, provided additional and informative insights into people's perspectives.

In contrast to the rather negative picture of hospital discharge services presented in the questionnaire data some good discharge practice was described here:

"a physio and an occupational therapist from the hospital came to the house and came over two weekends before he (husband) was actually discharged to see if there were any problems. So that was good, that worked well."

Sporadic and patchy integrated care was, also described, however:

"We've had one case conference, sorry two case conferences, where social services, the doctor, the nurse and home care have been in attendance. We've had two in 8 years and the last one was four and a half years since."

As with the other data sources, accounts reflected the variety of skills and personalities encountered within the health and social care workforce. Thus, one participant was very complimentary of a home carer's approach to working with her husband:

"she's absolutely excellent...goes for a walk every day and she'd go with him, and he falls an awful lotand she actually bothered herself to read some information that the Sister had prepared for her".

The Direct Payment scheme (where people are provided with money to purchase their own services) was praised by one participant for enabling him to have greater control over his wife's care package:

"The home care staff: it's written into [name of wife]'s care plan that any new members of staff have to be trained by me."

Direct payments seemed to equate with their original purpose in this man's estimation, as he appeared to feel empowered with regard to service provision. Unfortunately, though, this sense of empowerment was not consistent across the accounts of other participants, as in this description of arrangements for hospital discharge:

"I don't know, for example, when it is decided that my wife will leave hospital. These are fundamental things that if I'd have known two weeks in advance, or a week in

advance, I might have needed to do certain things at home that would have made it easier for me, and easier for my wife. But it doesn't happen that way. It's just a case of 'your wife can go home tomorrow'!"

The apparent lack of consultation in this and other accounts of discharge arrangements, seems to contrast starkly with the prevailing ethos of consumer involvement in NHS decision making.

3.4.1 Resourcing

Lack of resources was an issue brought up in interviews as elsewhere in the fieldwork process. One interviewee suggested that his daughter had been 'shunted around' different residential care homes because of funding problems. Difficulties in securing help were also prevalent in people's accounts and, in this extract, were linked with the apparent lack of a 'caring' attitude on the part of workers:

"I think it would be nice that they pick up the phone and say, 'you know is there anything we can discuss?'. I know I can do it, but as a carer it's just nice to know that you have a back up and that somebody cares – because at the moment you seem to be banging your head against the wall. Anything you want you have to fight for. I know we talk about the ideal world where you want other people to take an interest in your life and perhaps it sounds selfish, but then it would just be nice...I think this is where the system fatally lets... you down...you don't want to have to beg, and at the end I was begging for help."

The notion of having to fight for services within an apparently uncaring environment was an important theme within interview, focus group and questionnaire data.

3.4.2 Labels

The currently popular 'service user' label came in for some criticism within interviews, with some strong antipathy being displayed towards the term from carers:

"I detest it. She's not a service user, she's my wife!"

"I'm the carer of the 'service user', but I don't like the term service user. I don't think it conveys very much at all. I don't know what I would use in exchange for that; possibly client or patient, but not a service user"

One interviewee went on to give a very succinct illustration of the 'cultural differences' that may need to be understood for successful partnerships with health and social care workers. She describes how use of a particular medical phrase seemed to be instrumental in securing the help she needed for her son:

"Participant: Soon as I mentioned tissue viability I had a tissue viability specialist nurse in this house within 48 hours, which was fantastic. She gave us a dynamic mattress, which changed to a powered dynamic mattress, so that just made sure that the skin was moved all the time and I also had a vibrating recliner chair."

Interviewer: Are you saying that when they knew the jargon you got more help? Do you think that was it?

Participant: You have to speak their language, yes. I really believe that. You have to do it assertively without aggression."

Clear and assertive communication, combined with a good understanding of specialised language seemed to help this person in attaining her care objectives for her son. This obviously raises the question of how successful other people might be who are less assertive and less knowledgeable

about health care 'culture'.

Finally, although there were many accounts of good practice in coordination of care within this study, there were also many accounts of a lack of integration. The very difficult lifestyles that some people endure are made more difficult by uncoordinated service provision. This final extract gives an eloquent description of the additional anxiety that people may experience as a result. This participant's wife suffered from Multiple Sclerosis. She had been repeatedly invited to a number of breast screening appointments to which her husband accompanied her, only to find that the building was not accessible to a wheelchair, and that staff felt unable to use the screening equipment because of her medical condition. He tried to give the interviewer a sense of his daily caring experience and of the impact that such poorly coordinated services had upon him:

"Well let me give you an idea. My wife now is 54 and she weighs 11 stone. She's quadriplegic, she suffers from primary progressive degenerative MS, she's blind, she can't speak, she can't swallow any more, so she's peg fed. She's a very heavily insulin diabetic who needs blood testing constantly throughout the day and needs at least four injections of insulin every day ...in the night. She's incontinent, she's catheterised."

I've got my own stress I don't need any more."

There was much in the way of additional data to be explored within the interviews that we did not have time to present here. Future publications will make use of a broader range of interview data.

Chapter 4:

Discussion

4.1 Introduction

This study collected a large amount of data concerning the perspectives of people making use of health and social care services. We were moved by people's willingness to share often distressing personal experiences with us and to offer such a rich and detailed insights into their lives.

We feel that the overall aim of the study was achieved, as we gained a comprehensive overview of service users' perspectives upon integrated health & social care and of their associated perceptions concerning the strengths and weaknesses of the current workforce.

It is probably useful to reiterate the specific objectives of the study at this point:

- To explore service users' experiences of integrated health care;
- Identify service users' perceived strengths and weaknesses and future needs associated with integrated health & social care;
- Identify service users' perspectives about the quality of the current health & social care workforce;
- Identify dissonance between workforce and user perspectives on integrated care;
- Explore service users' beliefs about future requirements needed to deliver quality care within a health and social care context;
- Explore service users' experiences and perspectives of health care students within the NHS.

All but one of these objectives were attained. The only objective which was not realised was the identification of the dissonance between workers' and users' perspectives on integration. The aim had been to compare the data from the present study with that collected

in another of the 'Shaping the Future' work packages, which had focused on the perspectives of health and social care workers. Time restrictions meant that in the end this objective could not be realised. A reading of the workforce report, however, will allow subsequent comparisons to be made.

This discussion chapter will focus on the implications of this study's findings for the education and training of health and social care workers. It will also involve a discussion of methodological issues encountered and their relevance for similar research studies, and discuss the implications of findings for the 'consultation' agenda within current health and social care policy.

4.2 Discussion of methodology

The people who took part in this study were predominantly people with high dependency needs or their carers. They were not, therefore, necessarily representative of the wider population who make use of health and social care services. The participants for this study were specifically chosen, though, because they were likely to have had extensive experience of health and social care provision. As such, they had much to say on integrated health and social care and their accounts represent an authoritative source of knowledge on a neglected topic.

It is important to acknowledge that direct users of services and their carers are two distinct groups with differing needs in terms of health and social care. Both, however, can be described as service users; albeit that there are differences in their reasons for using services. Although this study represented the perspectives of both groups, a significantly greater part of the data was derived from the

accounts of carers. Both sets of 'voices' should be addressed with relation to integrated health and social care, but carers' perspectives are more likely to be heard than those who they care for. It will be important in future studies on service user perspectives to find innovative ways of accessing the views of such marginalised groups. This is an important goal in research terms but also with regard to the current policy goals of consultation and empowerment.

It was interesting to note the depth that the qualitative data added to the basic quantitative data within the study. Extracts of dialogue and verbatim comments were invaluable in interpreting the basic responses to the individual questions within the questionnaire. Qualitative data also often shed a quite different light on quantitative responses. For example, levels of satisfaction with partnership working recorded in the closed questions within the questionnaire were more positive than the written comments provided for the related open questions.

Problems have been noted with previous reports of satisfaction with respect to patient satisfaction surveys. Williams, Coyle and Healy (1998), for example, suggest that people's evaluations of services are inextricably linked with their perceptions of duty and culpability. Thus, even if users of a service have had negative experiences they may be likely to say they are satisfied if they don't see a service as culpable (something they perceive as 'not the fault' of the service). The additional qualitative data within this study was crucial in providing a context and means of interpreting the perspectives displayed through the structured, quantitative data. One must be cautious in making claims about satisfaction

based solely on the basis of ratings scales and survey data.

Another significant research issue to consider is the possibility that people may be nervous about making critical comments concerning the services they receive for fear of services being withdrawn. Whilst such perceptions may well have no clear basis in evidence one cannot ignore the potential influence of such beliefs on the veracity of research data. One of the focus group participants implied that she had been worried about services being withdrawn because of complaints she had made about service provision:

"Participant B: *The one who shouts the loudest gets the best service.*

Participant C: *And it shouldn't be like that... Because sometimes you'd feel you was a moaning parent and get yourself a reputation ...*

Participant B: *And then you worry a lot – you'd be frightened you have (the) service taken away."*

Although confidential research data is obviously not passed on to service providers it is reasonable to assume that some participants would be concerned about being open in their views lest the information get back to those who provide the services upon which they rely. Much emphasis was placed upon anonymity within this study: participants were assured that all data would be anonymised and that no personal opinions would be identifiable within the final report or associated publications. Where self administered questionnaires are completed in isolation and returned in the post, however, the supposed independence which Universities profess to enjoy may not seem so apparent to the people who provide the data. Again, though, the opportunity to make written comments in the questionnaire for

this study would suggest that people felt relatively comfortable in making critical comments of the services they received.

This study provided much valuable data on people's perspectives on integrated health and social care. However, if empowerment objectives are to be taken seriously it is important that future studies should involve 'service users' at the design stage and throughout the research process. Sincere approaches to empowerment involve sharing of power on the part of health and social care workers, but should involve the same in terms of researcher/researched power relationships. This may present a challenge to traditional academic approaches to research. An 'action-oriented' research agenda which responds to research questions identified by service users is a key means of ensuring that empowerment is an attainable objective, as opposed to a rhetorical phrase.

There was some good evidence of fieldwork approaches which appeared to be empowering for the individuals who took part. The people mentioned in Section 2, who arranged contacts and distributed questionnaires, seemed to gain much in the way of confidence and self esteem, and enhanced work opportunities for the future.

Participants themselves were very generous with their time, in expressing their thoughts, and in providing assistance in the organisation of fieldwork encounters. Many workers within voluntary organisations also provided a great deal of help with little in the way of reward. We had little in the way of resources in this project to offer reimbursement for participants or others who helped out with the

research. Much of what was achieved within this project was done so only with the goodwill of a large number of people. We are truly grateful for the help we received.

Goodwill is not an infinite resource, however, and the funding of related research studies need to include sufficient resources to recognise the types of contributions outlined above. This is an important ethical issue which needs addressing if people are to feel involved in health and social services research in a meaningful way.

4.3 Empowerment and consultation

Empowerment can be defined broadly as the ability of people to exercise control over the course of their own lives and in keeping with objectives which they themselves have identified. The data collected within this study did not suggest that participants felt empowered with regard to their use of health and social care services. There were some accounts given by people who felt a fair level of control over the organisation of home care services. Perceived control seemed to be an exception in this respect though. A majority of participants appeared to feel disempowered with regard to their abilities to exercise control over health and social care. A prevailing theme within the various discourses was that service users' and carers' perspectives were often not considered in relation to the decisions made about them. Participants apparently had to either 'fight' to have their needs respected, or their views were not 'listened' to by the people who were in a position to do something about them.

No collection of diverse perspectives can ever be depicted, however, as a one-dimensional view of any subject. There were numerous examples of

good practice described in relation to individual workers who listened to people's expressed needs and acted upon them. Again, though, a larger number of accounts suggested that people did not feel listened to, or consulted. A repeated request was for workers who would take time to listen to the concerns of people using their services. The picture portrayed in this study did not conform to the notion of engaged and involved service users, as depicted in the world of 'Patient and Public Involvement'. It seems that much greater effort should be expended by health and social care services to reach out and incorporate the views of service users; as opposed to waiting for people to take the lead in contacting them.

Those who make greatest use of health and social care services are likely to be those who find it the most difficult to express their views through conventional channels. If health and social care is ever to be wholly integrated it is imperative that users of services are consulted in a meaningful fashion. It was not at all evident from this study that participants felt themselves to be equal partners in the sense envisaged by policy pronouncements on integration and partnership working.

4.4 Integrated care?

The key reason for undertaking this piece of research was to find out something about the perspectives of people concerning the extent to which health and social care seems to be integrated. Within the accounts given clear examples of integrated services were described. Health and social care workers appeared to share information regarding people's care, and worked with each other to provide integrated services that addressed identified need. Where integrated care took place it appeared to serve its function well and was clearly welcomed by participants.

Less than half of the people who responded to the relevant item within the questionnaire, however, claimed to have encountered partnership working with respect to the care they received. This may have been because they did not know whether workers worked in partnership. Indeed, over two thirds of those completing the questionnaire did not appear to know if health and social care workers met together to plan their care. Of course, people who use services may not be concerned about who is providing them and whether they are integrated, so long as they receive a satisfactory level of care. The evidence presented in this study suggests, however, that participants were often unhappy with the level of care they experienced. Serious concerns were expressed concerning communication between different services and also concerning the crossing of professional boundaries. Unfortunately, the notion of 'passing the buck' to other workers in health and social services appeared to be a significant problem for some participants. Such ongoing reluctance to cross professional boundaries is exactly the sort of issue that integrated service provision is designed to rectify. The fact that it emerged as a significant area of concern for our participants is a worrying sign, and one which requires immediate redress in terms of management and training of the health and social care workforce.

Given the importance of joint working with regard to the areas of care explored here it seems surprising that participants appeared to have little knowledge of the extent to which inter-professional care was taking place. This dearth of knowledge implies a lack of commitment to partnership working on the part of professionals.

Fully integrated health and social care can only become a reality when the workforce pays credence to the achievement of integrated partnerships which involve users of services. The study also highlights the need for a concerted awareness raising campaign targeted at service users which explains both the process and benefits of integrated care. The current approach to integrated care still seems to reflect a practitioner dominated set of power relationships, rather than a situation where decision making power is shared equally amongst all stakeholders.

A pervasive theme throughout participants' accounts was a sense of vulnerable people with difficult lives having to struggle to secure necessary services. Social Workers were sometimes seen as failing to advocate successfully for clients in this respect. Given the stressful environments which many of these people inhabit the role of advocate is an important one to develop. Advocates could 'speak up' for service users in this respect and make their wishes known, and hopefully secure a better deal in terms of health and social care services. An independent advocate would be a preferable alternative to one which is allied with a particular working discipline such as Social Work.

4.5 Home care agencies

A consistent area of interest for participants was the quality of home care services. Some participants described home care services in very positive terms, with the attitudes and care provided by individual workers being picked out for much praise. The key measure for participants seemed to be the level of communication skills displayed; particularly the abilities to listen and to empathize. Home care workers who were judged to possess these skills were highly valued.

The attitudes and skills of home care agency workers were, however, more likely to come in for criticism than praise. The quality of home care was an issue that regularly provoked adverse reactions in focus groups, questionnaires and interviews. It featured so prominently because of the very real significance of such services to the quality of service users' and carers' daily lives. The most common complaints about home care services were: workers' apparent lack of knowledge regarding clients' medical conditions, a lack of basic communication skills and a lack of continuity in workers. There did not seem to be much evidence of home care workers communicating with other health and social service professionals regarding the care of clients.

We feel that the role of home care agency workers is a crucial one with respect to integration of health and social care, as it is these workers who represent the public face of services to many people. If home care appears to be of poor quality and is not seen to work in conjunction with other services it is very likely that the whole concept of integrated care will be interpreted as meaningless. Home care services are only one element of social care, but for our participants they were often the most important element within the health and social service continuum.

Of course, the dissatisfaction expressed with home care should be interpreted within the broader context in which many home care agency workers have to carry out their duties. They often have little time to spend with individual clients and appear to receive very low rates of pay for demanding and difficult work. The accounts of participants in this study would also suggest that they receive little in the way of formal

training. Home care work seems to be a very undervalued profession within health and social services. Much more attention needs to be given to the training of home care workers and to highlighting the central role that home care work plays within effective health and social care provision.

One other key issue of concern highlighted was the apparently disjointed services that sometimes seem to accompany discharge from hospital. There does not appear to have been much research attention given to this topic, but the data presented clearly suggests that it is an area of integrated care that needs further investigation. Again, this is an issue of much concern to people who have complex health needs and who may require regular stays in hospital. The concept of integrated health and social care is often couched in a general narrative concerning 'seamless services'. The return to community care from hospital based care is an event which should clearly function as a seamless service. This did not seem to be the case, however, for many of the participants in this study. Concrete discharge guidelines need to be enforced in hospitals, and arrangements for discharge negotiated with service users and carers. One would assume that such guidelines already exist, but there was little evidence of them being put into practice with regard to the care of people taking part in this project.

4.6 Implications for future education and training

This project has indicated several key areas to address in the future education and training of the health and social care workforce. For ease of reference and recall these are outlined in bullet point format below:

- Include clear models of good practice in integrated care in the training of health and social care workers;
- Extend service user involvement in training;
- Find ways of capitalising on obvious service user enthusiasm for training;
- Involve service users in interdisciplinary training sessions to enhance workers' appreciation of user perspectives;
- Place greater emphasis in training on the use of basic communication skills (especially listening skills) in direct client work;
- Proactive consultation mechanisms are needed to identify the types of services that users would like to see in place. Current arrangements are too passive – the service user has to take the initiative;
- More opportunities for health and social care workers to train together are needed to enhance crossing of professional boundaries/appreciate different professional perspectives;
- Significant increase in investment of training for home care agency workers;
- Establish professional qualification pathways for home care workers;

- Review pay scales for home care workers;
- Raise both workers' and service users' awareness of the meaning of integrated health and social care: that is, not only integration between work of different health and social care professionals, but also integration between work of statutory and non-statutory organisations, and between the work of home care staff and 'professionals';
- Emphasise that partnership working means partnership between workers and service users – not only between workers;
- Focus on ways of ensuring real rather than tokenistic involvement of service users with respect to partnership working;
- Address workload allocation of health and social care workers to allow time for meaningful interaction with clients.

Much of what has been envisaged here in terms of service improvement can only be achieved in an environment where the health and social care workforce have the time to devote to the forging of sustainable links with service users and other workers. There certainly appear to be many examples of good practice in integrated health and social care already in existence. But equally, there seem to be many examples of disintegrated services. The integration of health and social care is still a phenomenon very much in its infancy. The chances of it becoming an autonomous adult will depend upon the strategic commitment of resources to its upbringing.

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Appendix 1:

Focus Group Discussion Guide

Care provision

What type of care do you/partner/relative receive at moment?

Who provides it?

Do you know which services provided by health and which by social services?

Any care provided by voluntary/non-stat agencies?

Do your health and social care workers liase/get together?

Do you know how they do it/how often?

Attitudes to care

Quality of care you receive

Quality of health care received

Quality of social care received

Examples of good practice

Examples of bad practice

Views on liaison between health and social care workers

Does liaison help to improve the care you/relative receives?

Students

Any care ever provided by health & social care students?

Views on care provided?

Attitudes to the provision of care by students

What would you like to see in students' training?

Future needs

Do you see your/relative's care needs changing in anyway in the future?

Which agencies do you feel are best placed to meet future needs?

Confident about health and social care workers working together effectively in future?

Anything to be done to improve quality of health and social care you/relative will receive in future?

Aspects of care missing?

Any general thoughts on how service you receive could be improved?

For users

Anything you want to add from your perspective as users of services

For carers

Anything you want to add from your perspective as carers

Appendix 2:

Covering letter for questionnaire

Thank you very much for agreeing to complete this questionnaire.

We appreciate that your time is precious but we are really interested in what you have to say. Your answers are vital to help us find ways in which we can improve health and social care training.

The questionnaire enclosed has been designed to find out your views on how well the health care and social care services work to provide your care.

Here are a few helpful tips:

If you care for someone who uses health and social care services, please fill in this form from your own experience as a carer.

Please note we have not asked for any names, addresses or other personal information therefore, anonymity is guaranteed.

Please do not worry if you are unsure about how to spell some words or if your writing is wobbly. We will do our best to read everything you have written.

If you need help to fill the form in, you can ask someone else to help or you can phone this number for further advice on what to do.

Tel: 01772 893415.

We have included a list at the back of this questionnaire which defines the role of health and social care professionals and charitable organisations and also a list of contacts you might find useful.

Your help is very much appreciated.

Appendix 3:

Letter to professionals

Dear Colleague

**Re: 'Shaping the Future in Primary Care Education and Training Project:
Finding the Evidence for Education and Training to deliver Integrated Health and Social Care.'**

As the NHS Modernisation Programme requires partnership and collaboration between health and social care services, we need to enlist your help.

The perspectives of people who access these combined services are vital to developing future training and education for health and social care professionals.

The overall project is a collaborative initiative between the North West Development Agency (NWDA), the North West Universities Association, and seven higher education institutions from the North West of England.

For more information on the project you can log on to www.pcet.org.uk

The University of Central Lancashire has been given the remit to look at service users (or their carers) perspective on these services.

To this end please find enclosed ten research questionnaires which need to target persons who are using both health and social care services, or are the carer of a person accessing a combination of both services.

Whilst we recognise that your time is precious we would be grateful for the return of any completed questionnaires by the end of November (or as soon as possible after this date please) in order to meet the deadline of this project.

We are very keen to ensure that our findings are of benefit to all who are accessing services. If you would like feedback on the results please contact either Geraldine or Paul (details below).

Thanking you in anticipation.

Yours sincerely

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email: PJReid1@uclan.ac.uk

Appendix 4:

Research participant information sheet

Thank you for agreeing to be a participant in this project. The following information describes how you can make a contribution to the study and also ensures that you are aware of your rights as a research participant. (Full details of the project can be found in the accompanying Project Summary document).

The Project

The main aim of the project is to identify what is needed by the Primary Care workforce to deliver integrated health and social care services and also how we can identify this. In addition we aim to identify what education and training provision is currently to be found in the North West to support the delivery of such services and identify potential gaps in requirement. An important element of our project will be to ask the workforce what they consider their needs to be to deliver an integrated health and social care service, together with asking people who will be using these services for their opinions. The Project is being funded by the North West Development Agency (NWDA) and the Project team are experienced researchers from seven Higher Education Institutions in the North West of England.

The aims and outcomes of the Project

To be able to meet the above aims the work of the Project Team has been divided into a number of small Work Programmes (WP). You will have been invited to participate in one of these, as follows:

- To develop a tool that those involved in developing new and current integrated health and social care services will be able to use to measure what they need to achieve to ensure good practice;

- To establish a database of education and training provision in North West Universities, Colleges of Higher Education, Further Education Colleges and Primary Care Trusts;
- To identify what the health and social care workforce in the Primary Care sector consider necessary to deliver integrated health and social care services;
- To identify what current and potential users of Primary Care services consider necessary to deliver good practice integrated health and social care services;
- To develop and test a tool, which will assist Primary Care, organisations to identify the education and training needs of staff to deliver integrated health and social care services.

The way in which this information will be obtained will vary in each Work Programme. The two main ways in which you may be invited to participate are by completing a questionnaire or through attending a small group interview. Some participants will also be invited to participate in a one-to-one interview.

Focus Group interview

A **focus group interview** involves meeting with the research team (no more than two members) to be asked questions about your views on integrated health and social care services, what education and training is required to deliver these and/or experiences of using such services. (In particular what skills and knowledge are considered necessary to deliver this in order to ensure a good service).

The interview will normally take no longer than an hour and may be tape-recorded with your permission. This will be transcribed into a written

format by the researcher. A copy of this will be sent to you on request. All your details will be anonymised and all information will be stored in a secure, locked cabinet with access only to researchers in the project. Any tape will be destroyed once the project is completed.

If you are not happy to consent to the focus group interview (or one-to-one interview) being taped we would be grateful if you could let us know before the agreed date and we are happy to make alternative arrangements if you wish to continue to participate in the project.

If you agree to participate in a **one-to-one** interview the same conditions apply.

Questionnaire

You may be sent a questionnaire to answer. If you have you will notice that the only information we require of you is details such as job title, length of time working in your current place of work, or if a user of Primary Care services which organisation you represent and briefly how you came to be using the service itself. You are under no obligation to return the questionnaire. We would of course be happy to answer any queries regarding the project before you finally decide whether to do so or not.

The same conditions of security of data, anonymity of participants and confidentiality apply with regards to any questionnaire returned.

Taking part in the project

We are pleased that you have agreed to take part in the project. In doing so you are helping us to find answers which will be used to make recommendations regarding the education and training aspects of developing and delivery of integrated health and social care services in the

North West region of the United Kingdom. The need to have a workforce that has the skills and knowledge to meet current and future needs of people in the community is a key target of the NHS. With your help we can contribute to some of this work.

You do not have to take part. Even if you initially agreed to be interviewed you may withdraw at any point without giving reasons. If that is the case we thank you for considering the invitation and letting us know you no longer wish to be interviewed.

After the Project has finished

This is a three-year project. We will be making sure, at different intervals during this time, that people are kept informed of our progress and many of you will be invited to join us at these events. In addition we will be publishing reports and papers which focus on different findings from the Work Programmes. We wish to assure you that at no time will anyone, or most importantly any place, be identified unless written permission has been given for us to do so.

Decisions

If you are happy to take part now you have read this information we would be grateful if you could sign the attached consent form and either return to the address below or bring with you to the interview. We would be grateful if you could let us know your intention to attend at the chosen time and date.

Thank you for your time and look forward to meeting you.

We welcome any suggestions or questions regarding both the content of this information sheet or the attached Project Summary document.

Signed: _____

Researcher: _____

Date: _____

Address: Name of lead researcher/Admin Office

Address in full

Telephone contact number

Contact E-mail address

Appendix 5:

Research Participant Consent Form

As part of your agreement to participate in the research study being undertaken please could you take your time to read the following statements and if in agreement with your continued participation complete the responses and sign the consent form. (Details regarding return of the form and dates of focus group interviews are to found in the accompanying letter.)

The research team would like to thank you in advance for expressing your interest in taking part in the research. You are under no obligation to proceed any further with active participation in the focus group interview (or one-to-one interview).

Title of Project: _____

Name of Researcher: _____

	Yes	No
■ I have read and understood the information sheet for the above study and what my contribution will be.	<input type="checkbox"/>	<input type="checkbox"/>
■ I have been given the opportunity to ask questions (face to face, via telephone and e-mail).	<input type="checkbox"/>	<input type="checkbox"/>
■ I agree to take part in the interview.	<input type="checkbox"/>	<input type="checkbox"/>
■ I agree to the interview being tape recorded.	<input type="checkbox"/>	<input type="checkbox"/>
■ I understand that my participation is voluntary and that I can withdraw from the interview and any subsequent interviews at any time.	<input type="checkbox"/>	<input type="checkbox"/>

Name of Participant: _____

Signature _____ Date: _____

Name of Researcher
taking consent: _____

Signature _____ Date _____

Shaping the Future: Consent Form (Focus Group) Version 1.14.2.2003

Appendix 6

Shaping the Future in Primary Care Education and Training Project

Finding the Evidence for Education and Training
to deliver Integrated Health and Social Care.'

Questionnaire designed
to find out your views about the health
and social care you receive

Lancashire School of Health and Post Graduate Medicine
Faculty of Health
University of Central Lancashire
Preston

Are you? (please tick one):

☐

A person who is receiving help from health and social care

☐

A carer of someone who is receiving help from health and social care

About social care services

2(a) Please look at the list of health care services below.

Please tick the boxes which say how satisfied you were with each of those services in general.

Health services	Very satisfied	satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied
Local doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health centre nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
District nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health visitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital consultants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital discharge service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please write the name of the service

2(b) Please tell us what you liked about the health care services you have received?

About social care services

2(d) Please look at the list of social care services below.

Please tick the boxes which say how satisfied you were with each of those services in general.

Health services	Very satisfied	satisfied	neither satisfied or dissatisfied	dissatisfied	Very dissatisfied
Hospital social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day care centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please write the name of the service

2(e) Please tell us what you liked about the social services you have received?

2(f) Please tell us if there was anything you didn't like about the social services you have received?

About social care services

Student training

3(a) Have any of the health care services, or social care services ever been given to you (or the person you care for), by students in training? (please tick one):

☐

Yes

☐

No

☐

I'm not sure

3(b) If you said yes, Please name the service and give your views on the help given by the trainee.

Service _____

Comments

Service _____

Comments

Service _____

Comments

If you have more to say, please continue on the back of this sheet.

About social care services

4(a) Do you feel that the workers who work with you have been well trained to care for your needs or the needs of the person whom you are caring for? *(please tick one):*

☐

Yes

☐

No

☐

I'm not sure

4(b) Can you think of any ways in which we could improve the training of health and social care workers?

5(a) Do you think that people who use health and social services, or their carers should help with the training of health and social students? *(please tick one):*

☐

Yes

☐

No

☐

I'm not sure

5(b) How do you think that you could help with the training of health and social services students? *(please tick one if you think it would be a good idea):*

☐

We could all talk to the trainers in charge of training programmes

☐

We could attend training sessions to work with trainees and students

☐

We could take part in committees to develop better services

Other ways in which we could be involved: (please give us your ideas)

About social care services

5(c) If you ticked 'No' to question 5(a), please tell us why you think it would not be a good idea to be involved in the training of health and social care workers?

If you have more to say, please continue on the back of this sheet.

Working together

6(a) Sometimes health and social care workers may work together to provide your care. This is called partnership working.

Have you experienced this yourself? (please tick one):

☐

Yes

☐

No

☐

I'm not sure

6(b) If yes, can you tell us what it was like for you? Did the health and social care workers work well together?

Please tell us who the workers involved in care partnership were

For example, Health Visitor and Social Worker

Please name all workers involved at any one time

Very good

good

adequate

poor

Very poor

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About social care services

6(c) If you have anything else to say about your experiences of using these services, please use this space to tell us more.

If you have more to say, please continue on the back of this sheet.

7(a) Do you know if health and social care workers meet together to plan your care?
(please tick one):

☐

Yes

☐

No

☐

I don't know

7(b) How do you think this affects the quality of the care given?

8(a) Have you (or the person you care for) been admitted to hospital for any reason during the time you have been receiving care? (please tick one):

☐

Yes

☐

No

☐

I don't know

8(b) If yes, how well did hospital discharge staff communicate with the health and social care workers giving you care at home? (please tick one):

Very Good

☐

Good

☐

Average

☐

Poor

☐

Very Poor

☐

About social care services

8(c) Please use this space to make any further comments about your answer to question 8(b).

9(a) When some carers or health workers attend to you at home, they may leave a folder of notes with you. These are left so that the next worker knows what treatment/care you have had that day, and what other care you may need.

Do you have, or have you had any of these notes?

☐

Yes

☐

No

If Yes, go to 9(b)

If No, go to 9(c)

9(b) If you answered 'Yes', how do you think this has affected the quality of care given?

About social care services

9(c) If you answered 'No', do you think this would be useful for you to have a file like this in your home?

Yes, because:

No, because:

If you have more to say, please continue on the back of this sheet.

Is there anything else that you think we should know or anything else you might like to say?

Thank you for taking the time to complete this questionnaire.

Your answers are vital to help us find ways in which we can improve the services offered to you and/or those you may care for.

If you require any further advice or information concerning the use of health and social care services the following organisations (on the next page) may be of use:

Appendix 7

Some contacts you might find useful *(for you to keep)*

Patient Liaison Service (PALS)

Every Health care trust has a patient liaison service who offer a confidential information and advice service for patients, relatives and Carers.

Name of Organisation	PALS Manager	Contact Details
Lancashire Teaching Hospitals NHS Trust	Wendy Langtree	Royal Preston Hospital, Sharoe Green Lane, Fulwood, Preston, PR2 9HT. Tel: 01772 523146/522972 email: Wendy.Langtree@LTHTR.nhs.uk
North Cumbria PALS (covering North Cumbria Mental Health & Learning Disabilities NHS Trust	Rebecca Crawford	West Cumberland Hospital, Hensingham, Whitehaven, CA2 8JG. Tel: 01946 523818 email: rebecca.crawford@ncumbria-acute.nhs.uk
Central Manchester	Mark Carroll	Write to: PALS Manager Central Manchester PCT, GroundFloor, Mauldeth House, Chorlton, Manchester M21 7RL Telephone the PALS Office on 0161 958 4117 email: pals@centralpct
Cheshire and Merseyside	Sally	The PALS Manager FREEPOST (CS 91)1829 Building The Countess of Chester Health Park, Liverpool Road, Chester CH2 1YZ. Tel: 01244 650368 o

Patient and public involvement in health (PPI)

<http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/PatientAndPublicInvolvement/InvolvingPatientsPublicHealthcare/fs/en>

Commission for Social Care Inspection (CSCI)

Social care based issues, including, care in the home, care-home issues and social worker issues
www.csci.org.uk

Commission for Health Care Audit and Inspection (CHAI)

Health care based issues
www.chai.org.uk

Harry Cayton – National Director for Patients and the Public

Harry Cayton advises ministers, the Department of Health and the NHS on the involvement of patients and the public, on improving patients experience and on building a patient centred health service.

Harry Cayton

Dept of Health
Richmond House
79 Whitehall London SW1A 2NS

Tel: 020 7210 5417

Independent advocacies

Advocacy for people with learning disabilities Preston Advocacy

Geoff Holmes	Tel: 01772 524469
Advocacy Plus	Fax: 01772 524192

Care of: Catholic Caring Services	
218 Tulketh Road	Chorley and South Ribble
Ashton	Tel: 01257 263254
Preston	
Tel: 732313	

Appendix 8:

List of sources of health care/social care, description of services and responsibilities and care professionals

Health care professionals

Local Doctor/GP

Diagnosis and treatment of health problems who may also refer you to other services such as hospital specialist or social care agencies.

NHS Direct

24-hour telephone helpline giving professional advice to callers about health worries and emergencies.

Health Centre Nurse

Gives treatment in the surgery prescribed by the GP such as injections, blood samples, changing dressings etc.

District Nurse

Gives treatment in the home prescribed by the GP such as injections, blood samples, changing dressings etc.

Health visitor

Visits people in the home and gives advice on health matters.

Hospital consultants

Doctors with specialist skills and experience in particular medical fields.

Hospital nurses

Give bedside care and some treatment as prescribed by the hospital doctors and consultants.

Physiotherapist

Treats disease or injury by physical means, such as massage or exercises rather than by drugs.

Hospital discharge service

Check that people have enough local support to make it safe to discharge people from the hospital.

Hospital social workers

Visit at the hospital bedside to set up support services ready for hospital patient's discharge.

Patient liaison services (PAL's)

People who deal with people's complaints and concerns about health care services.

Social care professionals

Social Worker

Provide help and advice on personal needs and contact with other social services (like those below). They will also assess and arrange financial assistance for social care.

Occupational Therapist

Give advice, can provide physical aids (walking frames, wheel chairs etc.), assess and arrange for necessary alterations to your home(walk in showers, downstairs toilets etc.). Some of these services may be means tested.

Home Helps

Provide personal care such as bathing and household help such as cleaning and shopping etc. Only personal care is provided through the social services; household help is charged to the individual.

Day Care Centres

Provide opportunities to mix with others and to take part in social activities. They also provide a few hours valuable respite for carers

Podiatry

Provide foot care in clinics and hospitals

Respite care

Temporary care in residential homes provided via social services and paid for by the individual or through the voucher system arranged by social workers.

Voluntary services

Citizens Advice Bureau

Provide advice on Welfare Rights, Charities and associations, for example, Help the Aged; Age Concern; Scope; Alzheimer's Society; Sight Concern; etc.

Finally, you can contact the Ombudsman at:

Millbank Tower

Millbank

London SW1P 4QP Tel: 0845 015 4033

e-mail: OHSC.Enquiries@ombudsman.gsi.gov.uk

website: www.ombudsman.org.uk